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ABSTRACT

This study is a follow-up to a 1990 needs assessment of American Indians with disabilities in the Denver (Colorado) region. The study involved a content analysis of transcripts of three focus group meetings of Project Advisory Committee (PAC) members, American Indians with disabilities, and service providers. Overall, PAC members and service providers indicated that change had occurred and was continuing to occur in services provided to American Indians with disabilities following the needs assessment. However, in the consumer focus group, the American Indians reported no difference in their perception of service delivery since the needs assessment. They identified three areas of service which remained inadequate--transportation, dental services, and dissemination of information about services. Findings suggest that minimal change occurred and that an information gap exists between service providers and consumers. The need for better coordination among service providers was stressed. The report details focus group responses for: in-home outreach; case management; vocational rehabilitation services; employment opportunities; self-advocacy; community-building; health and wellness programs; efforts to train, hire, and retain Indian personnel; role of the University-based research team; role of the American Indian community; and linkages among service providers. Appendices include focus group questions and related material. (Contains 16 references.) (DB)

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The Assessment of a Model for Determining Community-Based Needs of American Indians with Disabilities: Follow-up in Denver, Colorado

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Final Report
1994

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In Memory and Honor of
Mr. Cecil Campbell

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Many of the people involved in the 1990 Denver needs assessment welcomed researchers from the American Indian Rehabilitation Research and Training Center back to Denver to conduct the 1993 follow-up; we gratefully acknowledge their kindness and support. In particular, the willingness of Michael Aragon and Vera Mitchell to serve as on-site research consultants was very much appreciated, as was the willingness of Margaret Tyon to host the focus group interviews at the Denver Indian Center. A sincere "thank you" is also given to the members of the Project Advisory Committee and to all participants in the focus group interviews (The names of the American Indians with disabilities who participated in the consumer focus group meeting are withheld in order to protect their confidentiality).

Project Advisory Committee

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Deborah Blackketter
John Compton
David Lee
Vera Mitchell
Margaret Tyon
James Weiland
Susanne Wiggins
Art Zamora

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Agency Representation in Focus Groups

Center for Technical Assistance and Training
Colorado Division of Mental Health
Colorado Rehabilitation Services
Denver Indian Center
Denver Mobility
Denver Options
Denver Public Schools Indian Education Program
Department of Human Services at the University of Northern Colorado
Eagle Lodge
Social Security Administration
Vocational Rehabilitation at Rocky Mountain Regional Brain Injury Center

SUMMARY

This project represented a follow-up to the study, "The Assessment of a Model for Determining Community-Based Needs of American Indians with Disabilities through Consumer Involvement in Community Planning and Change," conducted in Denver, Colorado during 1990. The design of the initial research called for a follow-up study to be conducted in three years. Thus the follow-up was conducted with the objective of determining the impact of the 1990 needs assessment. The follow-up was conducted through a series of three focus group interviews.

Throughout the course of the follow-up, researchers consulted with a Project Advisory Committee (PAC) made up of members of the Denver-metro community. In addition, two on-site research consultants were hired from the local Indian community. Specifically, these consultants, along with the PAC, assisted the AIRRTC-based researchers in: (a) validating the focus group format as appropriate for use with American Indians and for the purposes of the study; (b) identifying issues to be discussed in the focus groups; and (c) identifying consumers, American Indians with disabilities, and service providers to participate in the focus groups. Further, the on-site research consultants organized and facilitated PAC meetings and assisted the principal investigator as co-moderators of the focus groups.

The three focus groups, held during the first week of April 1993, included in separate meetings: (a) PAC members; (b) American Indians with disabilities, a majority of whom were interviewees in the study conducted in 1990; and (c) service providers representing various Denver-metro agencies. All of the groups were asked the same set of questions, of which the majority were derived from the recommendations made in the final report of the initial study. A stenographer recorded a verbatim account of the proceedings using a stenotype machine; these data were then subjected to content analysis.

PAC members and service providers indicated that change had occurred, indeed was continuing to occur, in services provided to American Indians with disabilities *after* the results of the needs assessment were made available to the Denver community; however, there was no agreement that all changes were a result of the findings of the study. Colorado Rehabilitation Services, for example, began sending counselors to the Denver Indian Center and to the Denver Indian Health and Family Services to meet with prospective clients; the agency attributed this action to the findings of the study. On the other hand, Eagle Lodge, a substance

abuse treatment program, reported writing a grant proposal to provide case-management services to Indian people with disabilities--an action reported to be unrelated to the AIRRTC study. [Currently, AIRRTC survey instrumentation from the 1990 needs assessment *is* being used clinically by Eagle Lodge staff as part of their case-management activities (Phil Sidoff, personal communication, September 1, 1994)].

In the consumer focus group, American Indians with disabilities reported no difference in their perception of service delivery since the 1990 needs assessment. They identified, for example, three areas of service which remained inadequate--transportation, dental services, and information about services. These participants were not aware of outreach services, case-management, or any specialized vocational rehabilitation service provided for older Indians with multiple disabilities. Consumers stated the need to come together and effect change through a grassroots movement. Participants in all three focus groups felt that the university-based research team should be available, following completion of a research project, to provide technical assistance and/or support to the community as necessary.

The follow-up findings have indicated that minimal changes in service delivery occurred for American Indians with disabilities since the completion of the AIRRTC needs assessment in 1990. While service providers pointed to a few specific actions they had taken with regard to improving services for American Indians with disabilities, the following remarks made by one consumer participant summarize the consumer perspective:

> *So with the survey that you took . . . three years ago, the information that you took back--you put together something and give it to people involved so that we can all take advantage of it, and you did do that, and none of us heard about none of this.*

At the time of the follow-up, an information gap existed between service providers and consumers; in addition, a coordinated effort among service providers to pool their resources and to find ways of improving their services to American Indians with disabilities, appeared to be lacking. In part, this lack of coordination may have been due to changes in leadership at two of the primary Indian service delivery centers in Denver--changes which occurred soon after the completion of the needs assessment. Finally, at the time of the follow-up study in April 1993, it appeared that service providers charged with serving the general community, had

not conducted specific in-home outreach, or tailored programs in any way, to meet the needs of American Indians with disabilities.

The Assessment of a Model for Determining Community-Based Needs of American Indians with Disabilities: Follow-up in Denver, Colorado

This project represented a follow-up to the study, "The Assessment of a Model for Determining Community-Based Needs of American Indians with Disabilities through Consumer Involvement in Community Planning and Change" (Marshall, Johnson, Martin, & Saravanabhavan, 1993) carried out through the American Indian Rehabilitation Research and Training Center (AIRRTC) in the Denver, Colorado metropolitan area during 1990. The primary purpose of the 1993 follow-up was to determine the impact on services provided to American Indians with disabilities as a result of the initial AIRRTC research.

The purpose of the 1990 study had been to determine the needs of American Indians with disabilities in a specific community, through the active involvement of Indian people with disabilities throughout the research process. The *Concerns Report Method* (Suarez de Balcazar, Bradford, & Fawcett, 1989), modified by AIRRTC researchers, was utilized in order to determine if its use would be relevant and beneficial to American Indian populations. Primary sponsoring agencies included: the Colorado Rehabilitation Services, the Denver Indian Center, and the Denver Indian Health and Family Services. Sponsoring agencies assisted the AIRRTC researchers in identifying subjects (hereafter referred to as interviewees) for the study. Interviewees were to meet four criteria; specifically, they were to be American Indians: (a) living in the Denver metropolitan area; (b) 14 to 70 years of age; (c) with a physical, intellectual, or emotional disability; and (d) not have alcoholism/substance abuse as their only disabling condition.

The initial research was conducted through face-to-face interviews from January 1990 through March 1990. Data from 100 interviews were included in the data analysis. The majority of interviewees were Sioux (67%) and female (55%), with an average age of 46.5. The interviewees reported an average yearly income of $6,086; however, the majority (58%) reported incomes of less than $5,000 per year. Interviewees reported having lived in Denver area an average of 18 years. One quarter of the interviewees were working for pay. The average yearly income of employed women was $9,667; the average yearly income of employed men was $10,800. On average, interviewees reported having approximately 2.8 disabling conditions; the most frequently reported disabling conditions included arthritis (37%), diabetes (33%), and substance abuse (24%).

Interviewees identified the need for outreach from social service agencies as their primary concern; interviewees reported obtaining information about services primarily through friends and relatives. Additional concerns included the lack of affordable housing, the lack of accessible transportation, and the lack of access to medical care. Only 2% of those surveyed reported receiving vocational rehabilitation services at the time of their interview.

At a public meeting held on April 17, 1990, at the Denver Indian Center, researchers shared the results of the study with the Indian community and requested input regarding recommendations for community change. Subsequently, within a few months of the public meeting, all interviewees, participants at the public meeting, and service providers involved in the research, were mailed a copy of a final report (Marshall, Johnson, Martin, & Saravanabhavan, 1993 [revised version]). The final report included, for example, the research findings and recommendations for community change.

Reid, O'Neil, Manson, Lundberg, and Joe (1990), in a panel discussion regarding the relationship of researchers to the Indian community, stated that community-based research requires both accountability to research participants and respect for the community. However, they agreed that "it is up to the community and to the tribe to take the information from research and develop culturally appropriate programming or follow-up." In that spirit, the following recommendations were made (Marshall, Johnson, Martin, & Saravanabhavan, 1993):

1. In-home outreach to identify individual needs should be conducted by those agencies wishing to serve American Indians with disabilities.

2. Case-management services should be available through Indian service agencies to ensure that basic needs are met.

3. Vocational rehabilitation services, which focus on the special needs of an aging work-force with multiple disabilities, should be made available within the Indian community.

4. Increased employment opportunities must be made available.

5. American Indians with disabilities in Denver need to organize themselves as a community.

6. Service agencies should provide education and information to American Indians with disabilities on their legal rights, especially employer accommodation to disability and accessibility issues.

7. Indian health agencies should develop education and information programs for the general Indian community that stress the "health and wellness" of disability.

8. Service agencies in Denver must renew their efforts to train, hire, and retain American Indians to serve this population.

The research question addressed in the 1993 follow-up study: "Does the information generated by the *Concerns Report Method*, result in improved rehabilitation service delivery to American Indians with disabilities in the target community?," was answered through the use of focus group interviews. This methodology is explained below.

METHODOLOGY

As a first step in conducting the follow-up study, two on-site research consultants, Mr. Michael Aragon and Ms. Vera Mitchell were hired. The research design and procedures were finalized in consultation with the on-site research consultants and a project advisory committee. Data were collected through focus group interviews, defined as "guided group discussions, intended to yield information on a specific topic from a selected population" (Ward, Bertrand, & Brown, 1991, p. 267). Lederman (1990) identified five "fundamental assumptions upon which the method rests":

1. People themselves are a valuable source of information, including information about themselves.
2. People can report on and about themselves, and they are articulate enough to put into words their thoughts, feelings, and behaviors.
3. People need help in "mining" that information, a role served by the interviewer, or researcher, who "focuses" the interview in the focus group interview.
4. The dynamics of group can be used to surface genuine information rather than creating a "group think" phenomenon.
5. The interview of the group is superior to the interview of the individual (p. 118).

Focus Groups in Social Sciences

In regard to the use of focus groups as a research methodology, Festervand (1985) noted that "numerous changes have occurred in the health care industry to improve the overall quality of services delivered. One of the most profound developments has been the widespread adoption of marketing orientation and associated strategies, techniques, and tools" (p. 199). Ward, Bertrand, and Brown (1991) found that, as a "stand alone" methodology, focus groups have yielded results similar to those obtained from surveys . . . " (p. 269). Specifically, these researchers concluded that the data obtained from focus groups would have led program planners to the same conclusions regarding program design as would the results of the surveys" (p. 282). Basch (1987) suggested that focus groups could be used, for example, to assist the researcher in interpreting and explaining data from quantitative studies, in conducting formative and summative program evaluations, and in identifying barriers to innovative program implementation. Researchers have also found that it is possible to address very sensitive and personal issues through focus group interviews (Basch, 1987; Nix, Pasteur, & Servance, 1988).

In the area of rehabilitation research, focus group methodology has been employed "with deaf faculty and staff working in a post-secondary education setting" to investigate the effectiveness of simultaneous communication (Newell, Stinson, Castle, Mallery-Ruganis, & Holcomb, 1990, p. 394). Persons with deafness also participated in focus group interviews "as part of a needs assessment on technology for deaf and hard of hearing people" (Harkins & Jensema, 1988). Lederman (1982) utilized focus groups "with identified high apprehensives" to explore issues related to communication apprehension or fear of talking. Elbeck and Fecteau (1990) reported using focus groups with psychiatric patients, primarily persons diagnosed with schizophrenia, to identify issues for a patient satisfaction survey instrument.

According to Lederman (1990) "the [focus group] technique requires the care of any systematic data collection, despite the fact that in format it appears to be simply a group discussion" (p. 126-127). Research studies utilizing focus group methodology may be broad in scope; for example, Basch, DeCicco, and Malfetti (1989) carried out a study that included "40 focus group discussions . . . with 316 volunteers . . . in 10 cities." On the other hand, representing a design more narrow in scope, Newell, Stinson, Castle, Mallery-Ruganis, & Holcomb (1990) chose to use "six focus groups, with five or six deaf professionals in each" (p. 394).

Focus Group Composition and Structure

According to Krueger (1988), "focus groups are usually composed of people who do not know one another; ideally, it is best if participants are complete strangers. In some communities, this is virtually impossible; nevertheless, close friends or those who work together should not be included in the same group" (p. 28). The position that focus group members should be strangers to one another in order for them to talk freely is shared by most researchers who have utilized this methodology (see, e.g. Lederman, 1990). However, focus group members should have "similar backgrounds" and be brought together to discuss a common interest (Krueger, 1988). Researchers agree that the focus group interview should not be conducted with more than 12 participants; the minimum recommended number of participants varies between six and eight (see, e.g. Basch, 1987; Festervand, 1985; Krueger, 1988). Festervand (1985) has stated that "there is no hard and fast rule" in terms of the number of focus group interviews or sessions that should be held on given topic. Lederman (1990) reported that a focus group generally lasts from one and one-half to two hours; Basch (1987) commented that focus groups "usually last one to three hours." The focus group moderator "is expected to cover a series of questions on a pre-established discussion guide. However, the format of the discussion is spontaneous, and participants are encouraged to freely discuss their opinions and feelings on these topics" (Ward, Bertrand, & Brown, 1991, p. 267).

Advantage Over In-depth Interviews

According to Basch (1987), "there are several reasons why a group interview may be advantageous over a series of individual in-depth interviews" (p. 434). He noted that in a focus group interview:

1. The interaction among respondents may lead to a more relaxed atmosphere "since individuals are not expected to respond to every question or issue . . . ."
2. The group interaction may allow for issues to be generated and concerns voiced that would not have come up during an individual interview.
3. "Group pressures may inhibit individuals from providing misleading information . . ."
4. The "turnaround time" for focus group interviews to be completed can be shorter than that for individual interviews, and they can be more economical (pp. 434-435).

Limitations of Focus Groups

According to Krueger (1988) "the concern about familiarity of participants is really an issue of analysis. . . . Were the findings related to the issue being discussed or could the comments have been influenced by past, present, or the possibility of future interaction with other group members?" (p. 29). Second, the focus group "must be conducted in an environment conducive to conversation. These factors often present logistical problems and may require participant incentives . . . ." (Krueger, 1988, p. 47). Third, focus groups "do not provide a sample of the population from which to generalize and draw inferences" (Lederman, 1990, p. 126). In this regard, Basch (1987) noted that "input obtained from participants is not intended to reflect how strongly these feelings or opinions are held. That would require a quantitative approach in which strength of conviction is specifically measured. Non-probability, purposive sampling is used most frequently, thus findings are not generalized to larger groups" (p. 414). Fourth, ". . . only individuals who are capable and willing to verbalize their views can be studied in focus groups" (Basch, 1987, p. 432). Finally, "the results of the focus group are tied directly to the quality of the group moderator who may introduce bias into the process" (Festervand, 1985, p. 201).

Project Advisory Committee

The purpose of the project advisory committee (PAC) was to review and confirm the proposed methodology of the follow-up research. Additionally, PAC members were to assist in developing the questions to be asked during the focus group interviews. At the beginning of the follow-up study, a letter describing the proposed research was mailed to 41 service providers/community members throughout the Denver metropolitan area, as well as to all interviewees of the 1990 needs assessment. Both service providers and interviewees were asked to participate in the follow-up, either as members of the PAC or as focus group interviewees. Nine individuals volunteered to participate in the study as members of the PAC; a 10th individual was asked to participate on the PAC by on-site research consultants [see Acknowledgements].

Mr. Michael Aragon contacted each of the PAC members and reported their suggestions/concerns during conference calls with researchers based at the AIRRTC. The PAC held an initial face-to-face meeting at the Denver Indian Center on March 16, 1993. In terms of the research process, the PAC: (a) found focus group

methodology appropriate for the study, (b) suggested that demographic data providing a profile of the consumer focus group participants be collected, (c) approved the time schedule/structure of the focus groups, (d) agreed that the focus group questions should be derived, in part, from the recommendations included in the final report of the 1990 study (Marshall, Johnson, Martin, & Saravanabhavan, 1993). Additionally, members of the PAC suggested names of service providers who they believed should be requested to participate in a service provider focus group.

Population

Participants in the 1993 follow-up study were American Indians with disabilities (also referred to as consumers), as well as service providers and interested community members. Specifically, the subject population included:

1. American Indians between the ages of 14 and 70 who had a physical, intellectual, or emotional disability and who lived in the Denver metropolitan area; individuals who had substance abuse as their *only* disability were not eligible to participate in the study.

2. Service providers from federal, state, and local agencies that provided services (or would be expected to provide services) to American Indians with disabilities; interested community members also participated.

Consumer Participants

Consumer participants were recruited through a letter which was mailed to 92 of the original 100 interviewees (Eight persons no longer had known mailing addresses). The letter described the objectives of the follow-up study, the focus group interview methodology, and requested the participation of the interviewees in the follow-up (see Appendix A). The letter also stated that consumers would be paid $25 in compensation for their time, transportation, or other expenses incurred as a result of their participation in the follow-up.

Of the 92 letters sent to the former interviewees, 38 were returned to the AIRRTC for reasons such as: (a) "moved; left no forwarding address," (b) "deceased," and (c) "forwarding order expired." On-site research consultants telephoned or made face-to-face contact with former interviewees who had not responded to the mailed request to participate in the follow-up. It was found that an additional five of the former interviewees were deceased; five had moved from the state.

Eleven former interviewees agreed to participate in the consumer focus group. In addition, six consumers, suggested by either former interviewees or the on-site research consultants, agreed to participate. These 17 consumers were asked to complete the *Profile of Focus Group Participants* form (see Appendix A) in order to determine: (a) demographic profiles of the consumer focus group participants, (b) time preference for the focus group and, (c) need for sign language or Native language interpreters.

Consumer profiles. Ten American Indians with disabilities participated in the consumer focus group interview; seven of these individuals had participated as interviewees in the 1990 study. Additionally, a mother of one consumer participated. Demographic information was collected from the consumer focus group participants. A majority (70%) of the 10 consumers were Sioux (see Table 1), with a mean age of 56.6. With the exception of one person who was 29, all participants were 50 or older (see Table 2). The majority (80%) of the participants reported having diabetes (see Table 3). Two persons reported having multiple disabilities.

Table 1
Tribal Affiliations of Consumer Participants (N=10)

Tribal Affiliation	Count	Percent
Sioux	7	70%
Navajo	2	20%
Seminole	1	10%

Table 2
Age of Consumer Participants (N=10)

Age	Count	Percent
29 years or below	1	10%
30 - 49 years	-0-	-0-
50 - 55 years	4	40%
56 - 59 years	1	10%
60 - 65 years	-0-	-0-
66 - 70 years	3	30%
71 years or over	1	10%

Table 3
Disabilities Reported by Consumer Participants (N=10)

Disability	Count*	Percent
Diabetes	8	80%
Arthritis	2	20%
Breathing problem	1	10%
Cirrhosis of liver	1	10%
Heart condition	1	10%
Seizures	1	10%

*Note. Count totals more than 10 as 2 persons reported having multiple disabilities.

Consumers described their disabling conditions as follows:

I got diabetes and the one thing that this thing bothers me with is it gets me real tired in the afternoon. Along about 3:00 o'clock or 4:00 o'clock or such, I am real tired and there's things I want to do; you can't do it. Just too tired, got to lay down. And this is one of the things that I don't like about it. And I take insulin both in the morning and in the evening. And it makes me grouchy.

I have a breathing problem. I can't do anything strenuous and I also have a weak esophagus muscle. I can't do any lifting. And I also have diabetes and arthritis. And I can't get sufficient exercise to lose any weight.

I'm diabetic and I am also allergic to the sun so that keeps me from going outside and walking or doing anything.

My problem is . . . I don't have enough strength. [It's] diabetes. And there are times that I don't feel good . . . I can't do anything. . . . I get tired easily. . . . And my weight is another problem also and it has just been going up and down. And my sugar is not well taken care of. So, I am taking insulin and otherwise I'm okay. But my left shoulder is not as strong as my right so I can't be lifting or reaching for things with my left arm.

Seems like everybody is talking about diabetic. I'm diabetic too. . . . I been diabetic for 15 years, but I had ups and downs, but I always stuck with the doctor, what he wants me to do. But, most of the time I stay pretty heavy; that was my problem. . . . About a year ago now, I had a heart attack and that was the hardest experience that I ever seen and been through it. . . .

I'm diabetic too. . . . I'm a diabetic for 21 years now and I'm still using that pill. And I think it is really hard to be on a diet because of you try not to eat sweets then all of a sudden you could have a sugar attack.

I have cirrhosis of the liver. I used to work all the time but not anymore. I can't do things I used to do. I get real bad nosebleeds when I work too hard or stay on my feet too long my ankles swell up. . . . I really miss working. . . . If I could learn something to do sitting down, maybe I'll go back to work. But most of the work I do is on my feet and lifting and stuff like that.

I'm a diabetic. . . . But I get tired too, you know, stuff like that.

. . . He [son] had spinal meningitis when he was a baby and that causes him to be an epileptic so he has seizures. But that keeps him from, you know, doing a lot of things that he wants to do. . . . He has gotten himself hurt lot of times playing basketball and that's his disability. . . . He used to be overweight when he was taking a different medication; they made him eat more. Then, they switch his medication to a different kind of medication and that's when he lost all that weight. . . . He used to be way overweight and it's the medication that caused it.

Service Provider/Community Member Participants

Two groups of service providers participated in the focus group interviews: (a) members of the PAC and (b) service providers who had *not* been involved in the 1990 needs assessment.

PAC focus group. Five members of the PAC participated in the focus group interview. The PAC focus group was:

1. Considered a pilot effort in order to test the process before researchers conducted the consumer and service provider focus groups.

2. Expected to be favorably biased toward the follow-up and to the researchers because of their PAC involvement in 1990 needs assessment.

Service provider focus group. Seventeen potential participants of the service provider focus group were suggested by members of the PAC as well as by the on-site research consultants. Potential participants were contacted by telephone or in person by an on-site research consultant who explained to them the purpose of the follow-up project and requested their participation in the focus group. Additionally, each potential participant was mailed a letter inviting her/his participation as well as an *Executive Summary* of the 1990 needs assessment (Marshall, Johnson, Martin, & Saravanabhavan, 1991). Nine persons participated in the service provider focus groups.

Instrumentation

As stated earlier, the major objectives of the 1993 follow-up study were to determine: (a) the impact on services provided to American Indians with disabilities as a result of the 1990 needs assessment and (b) the efficacy of a specific model in conducting community level needs assessments with American Indians with disabilities. Data were obtained through the use of focus group methodology and triangulating sources of information--collecting data from not only consumers, but also from two groups of service providers.

The PAC assisted researchers in developing the protocol and structure of the focus groups. The PAC also assisted researchers in developing appropriate focus group questions which would elicit answers to the research questions. Eight of the focus group questions were based directly on the recommendations from the 1990 needs assessment; additional questions asked of consumers and service providers were recommended by the PAC as part of the pilot feedback after the PAC focus group (see Appendix B). Consumer participants also contributed to the questions asked of services providers. For example, consumers asked the co-moderators if specific information could be obtained such as: "If a person is on SSI, how much [additional income] can they make per month [without losing the SSI benefits]?" Consumers requested that services providers share information regarding the availability of: (a) no-cost transportation to and from hospitals, (b) subsidized prescription medicine, (c) rehabilitation services, (d) "housing for handicapped people" and, (e) dental services. Service provider participants were informed of these consumer needs and were asked to send to the Denver Indian Center any brochures or other information that would address the consumers' concerns.

Procedure

On-Site Research Consultants

The on-site research consultants hired to coordinate the follow-up research activities in Denver acted as liaisons between the AIRRTC-based researchers and the project participants. Sister Marie-Therese Archambault, the on-site research coordinator for the 1990 needs assessment, was initially contacted by the principal investigator (PI) and asked to serve as the on-site research consultant for the follow-up. While unable to serve in the research consultant capacity, she was able to serve on the PAC. Ms. Vera Mitchell (Sioux), a PAC member during the 1990 needs assessment and Mr. Michael Aragon (Pima), an interviewer during the 1990 needs

assessment, agreed to serve as on-site research consultants, sharing the responsibilities of local coordination activities. These activities included, for example:

1. Identify at least one consumer who would participate on the PAC.
2. Suggest participants for the service provider focus group.
3. Locate interviewees of the 1990 needs assessment for whom the AIRRTC no longer had a valid mailing address.
4. Confirm location for focus group interviews.
5. Assist in arranging for meals to be provided to focus group participants.
6. Assist with identifying a professional who could record the proceedings of the focus group interviews.
7. Follow-up with 1990 interviewees by telephone or in person and request their participation in consumer focus group.
8. Arrange for the transportation of consumer focus group participants, if necessary, as well as any needed accommodations, such as sign language or Native language interpretation.
9. Facilitate meetings of the PAC.
10. Serve as co-moderators of the focus groups.

In regard to this latter activity, Krueger (1988) stated that "complementary moderators work together but represent different levels of expertise with focus groups and the topic of discussion" (p. 164). Thus it was determined that the PI and Mike Aragon would co-moderate the PAC and service provider focus groups, while Mike Aragon and Vera Mitchell would co-moderate the consumer focus group.

Conducting Focus Group Interviews

Three separate focus group interviews were held at the Denver Indian Center (DIC) on April 6, 1993 (PAC focus group), April 7 (consumer focus group), and April 8 (service provider focus group). On the day prior to the first, or pilot, focus group interview, AIRRTC researchers and the on-site consultants met at the DIC to finalize procedures for conducting the focus groups. The research team also met with Ms. Margaret Tyon, Director of the Senior's Program at DIC, to review the classroom setting in which the focus groups were to be conducted.

The setting. Interviewees were seated at a rectangular table; the co-moderators sat at the head of the table where all interviewees could see them clearly. A name-plate was placed in front of each interviewee so that the proceedings reporter could easily record who was speaking. An overhead projector was made available, through

the Denver Public Schools Indian Education program, to display focus group questions.

The structure. As data in this study were the words spoken by interviewees, careful attention was paid to recording the proceedings verbatim; a professional reporting firm was hired for this purpose. The reporter sat unobtrusively in the room and recorded the proceedings using a stenotype machine; additionally, the reporter recorded the proceeds on audiotape in order to ensure an accurate recording of the data.

Persons observing the process included a doctoral student from the University of Wisconsin-Stout who intended to replicate the 1990 needs assessment on a reservation in Wisconsin for his dissertation research, an assistant to the director of the DIC Senior program, and two additional DIC employees.

Focus group meetings began at 11:00 a.m. each day and followed a structured agenda (see Appendix C). Focus group participants were informed of the following "ground" rules: interviewees should express themselves freely; names would not be associated with comments in the published final report unless participants requested that they be identified, or gave their permission to be identified; participants were asked to speak one person at a time; participants were asked to sign an *Informed Consent Form* explaining their rights as participants in the research. Additionally, consumer interviewees signed an *Interviewee Billing Statement* in order to receive $25 in compensation for their time, transportation, or other expenses incurred as a result of their participation in the focus group (see Appendix D).

The process. Each of the focus group questions were asked by one of the co-moderators; concurrently, the question was displayed visually using an overhead projector. This enabled interviewees to focus on the various aspects of each question. A lunch was provided on-site at the DIC each day; this allowed participants to have a break from the research process, but also sufficient time to fully address the research questions.

During the consumer focus group, one of the observers interrupted the focus group process in order to make a comment. This created the necessity of adding an additional "ground rule" to structure the focus group process; specifically, the co-moderators asked that observers write down any comments/clarification statements they felt essential to communicate and give to the co-moderators. Remarks made by the observers were not considered as data, and were not included in the data analysis.

Data Analysis

As mentioned earlier, with the exception of demographic information, "the data generated from focus group discussions are the words spoken by the discussants . . . and all of the behaviors associated with those words" (Lederman, 1990, p. 124). Regarding the latter, Lederman has suggested that "explicit articulation of the interviewer's impressions of the group and group process" be included in the focus group summary report (p. 125). As Krueger (1988) pointed out, "numbers and percentages are not appropriate for focus group research and should not be included in the report. . . . The analysis process involves consideration of words, tone, context, non-verbals, internal consistency, specificity of responses, and big ideas" (p. 119).

Verbatim transcripts of the focus group data averaged 130 double-spaced pages for each interview. These transcribed data were verified by comparing the "hard copy" with the proceedings as recorded on audio tapes, with any necessary corrections made. The data verification process took approximately two weeks to complete.

The data were analyzed using *The Ethnograph* (Seidel, Kjolseth, & Seymour, 1988), a text analysis software program which can facilitate the mechanical aspects of qualitative data analysis. For each question asked in the focus groups, responses were subjected to content analysis and summarized according to similar themes.

RESULTS

Summary statements, along with direct quotes which exemplify participant responses, are presented for each of the topics discussed in the focus groups. The reader is reminded that each of the focus groups, that is, the PAC focus group, the consumer focus group, and the service provider focus group, were held separately--the responses of the consumers, for example, would not have influenced the responses of the service providers.

In-home Outreach

Responses by PAC Members

PAC members were *not* aware of any specific outreach that *focused* on the needs of American Indians with disabilities. Comments included:

[The Indian Education program is] becoming more active in attempting to outreach parents in getting them to become a bit more involved in the education efforts, educational efforts of the Indian kids here in some of the inner-city school districts.

. . . the Denver Indian Family Health Services as well as the Denver Indian Center have taken some measures to reach out in the community and make the attempt to, for example, engage elder folks to become more involved with the meals program.

Social Security . . . they are doing a lot of efforts and right now are in the planning stages of how to expand services to the American Indian population--not limited to the Denver-metro area, but throughout the region.

I don't believe that rehabilitation to any great extent provides in-home outreach efforts specifically to American Indians with disabilities.

I sit on the State steering committee for a transitions change grant, which is a grant given to the Rocky Mountain Resource and Training Institute and Department of Education for youth transitioning from school to work. . . . One of the committees we are going to establish is one on American Indian youth. . . . Through that committee structure some of that in-home outreach would occur because of the youth. And that's what I'm hoping for anyway.

PAC members described the past efforts and/or future plans of their respective agencies regarding in-home outreach efforts:

. . . we had offered through an establishment grant process in rehabilitation whereby the concept was that we would hire American Indian aides to work from the Indian Center to do the outreach that was needed . . . , [and] with the transition at the Indian Center . . . the grant did not get processed or even submitted. So, that effort was not very successful.

After the study we assigned a counselor to the Indian Center, and one to the Indian Health Services as liaison with them and Rehabilitation Services.

Right after the study was concluded there was a bit on the press here in Denver and I think that had a little bit to do, but like everything else, it died.

. . . following the study, we [the Colorado Planning Council for Developmentally Disabled] . . . , through a committee that was established in the Council that we called a minority affairs committee, made an effort to identify Native Americans to sit on that committee. And we had a couple of people that came to a couple of meetings and we tried to include them. And something happened on the way to the forum that did not continue.

Four factors contributing to the lack of focused out-reach efforts were identified and included: (a) changes in leadership at the DIC and subsequent failure to submit a grant application, which, if funded, would have provided for the establishment of an outreach program; (b) lack of involvement of Indian people on the policy-making boards and advisory councils of various state and local agencies; (c) lack of human resources within Indian community to ensure representation on all relevant boards and councils; and (d) the "aggressive" and/or "assertive" postures which Indian PAC members felt were necessary to effectively serve on such boards. Comments included, for example:

> *. . . the overall experience has generally been it's difficult to continue the interest unless you have people there that can constantly keep reminding you that a need exists. If you leave it to the agencies, my experience has been it really doesn't happen because they have too many priorities and this doesn't happen to be one of their highest priorities. . . . Very seldom are the questions asked by the members of those groups about minorities in general and Indians in particular unless you happen to have an Indian present there. And I personally get tired after a while having to raise those questions. But, if I don't raise them, they don't get raised.*

> *. . . the resources are very limited in terms of the people in the two specific agencies that are Indian specific, DIC (Denver Indian Center) and DIHFS (Denver Indian Health and Family Services). . . . Why is it that we just don't have that many Indians that can be represented on committees or identified as important figureheads, as service agents? It is because there just aren't that many that are engaged in the systems that exist today.*

> *I think the problem with serving on boards is . . . I serve on a non-Indian board. . . . I was invited to come and sit in on the meetings and bring up issues of Indian families and whatever. And I did attend the meetings and then, I was asked to serve on the board. And I had to give it a lot of thought because they're all non-Indians. . . . And if you walk into a room, you know, full of non-Indians and you are the only Indian there, you get sort of a funny feeling, especially the way I grew up, because we faced a lot of discrimination when I was growing up on the reservation and you still have that tendency to feel that way. So it was hard for me. And I didn't know too many people there. . . . And after about four meetings, I began to feel more comfortable and I had input on what's going on. That's what happens to a lot of Indians, even if they're asked, even if they're invited to come and sit on a board, they just don't. You have to be sort of aggressive, I guess, you know, and say, "I'm going to stay on this board and see what happens."*

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Often times, I feel very ineffective. I'm sitting there; I'm the only Indian person. Perhaps, I'm not aggressive enough. I have a problem with--you know, . . . being aggressive or assertive, . . . where does one start and the other begin? . . . Was I being effective or was I just sitting there listening? These other people get up there and shout; I sit back. Should I say something or shouldn't I? . . . How personal should I take some of these things, or not personal. Yeah, I have a problem sitting on boards because, you know, I find aggressive people to be very offensive.

PAC members suggested that a multi-pronged approach would be necessary in order to develop an outreach program that would reach American Indians with disabilities, including: (a) networking, (b) renewing efforts to submit a grant proposal for employing persons to outreach American Indians with disabilities, and (c) advocating for a specialized vocational rehabilitation program (similar to the tribal controlled VR projects [Section 130 projects]) to be funded for urban American Indians. Comments included, for example:

. . . there are some networks out there that you better learn who belongs to what group and how the decisions get made. . . . Everybody that's there, I get a sense, is representing a special interest group--and they're valid. I mean they're valid issues that get surfaced. It's interesting to go to those meetings and you learn a lot because of the politics. A lot of times it's more what isn't said than what's said that's important. . . . You know, there are some gods out there, in particular disability groups, that you better know who they are if you're going to have any impact on those systems.

I would like to explore the possibility and the feasibility of re-enacting the establishment grant if there is someone who can promote that from an identified entity, whether it be the Indian Center or somewhere else.

I had something to do with the Section 130 projects, projects to serve people on reservations. . . . And the question was raised several times, "what are we doing in urban areas? . . . Could we run something like that in urban areas?". . . It's difficult to continue the interest unless you have people there that can constantly keep reminding you that a need exists.

Responses by Consumers

Consumers, in general, were not aware of any in-home outreach provided by any service agency. One participant cited the example of outreach conducted through a church--the members voluntarily helped one another. Another participant felt that the DIC should have a program that would outreach people with disabilities, as well as elders, and assist them with various needs. Comments

included, for example:

> *I don't know of any, that's why I just shook my head. I don't know of any. I haven't heard of any.*
>
> *I never heard of nobody coming into your home. I know we have to go to their offices. But, I never know of anybody coming into your home.*
>
> *This I would like to see with the Indian people, to help each other more. Don't make no difference what it is, if you can do it, then we need to do it. . . . The young people . . . , they ain't going to be helping you. They don't believe until they get to our age, then they'll know. But this I would really like to see.*
>
> *I work with the home health agencies . . . and that's part of our job. They get us to go in and we take them to the store; we're allowed two hours with them, or we go in and give them a bath or give them--cook them a meal. . . . Like I'm an Indian and working with an all White community. Why don't they have program like that here [at the DIC]? And train them. That's all I do now is sit with elderly patients, take them to the store, take them back and that's all I have to do. But I think the Indian Center should have a program like that.*

Responses by Service Providers

Service provider participants discussed at length issues related to outreach--primarily identifying the problems they faced in providing outreach services. Problems included lack of funding and lack of personnel, even for those agencies providing some degree of outreach to their service populations. Thus while some agency representatives reported having some outreach services (though none with the specific goal of case-finding as regards American Indians with disabilities), others did not engage in outreach. For example:

> *[Regarding the] public mental health system, and . . . in-home outreach, it does not formally occur. If it should occur, it would be coincidental to some other work or ancillary to some other activity, that might be taking place. But, formally it does not occur and formally there is no mechanism, at least in metro-Denver, . . . for this type of in-home outreach.*
>
> *I'm not aware that there is any type of service that is in-home outreach to people with brain injuries, period, and certainly not to Native Americans.*
>
> *Metro Mobility does not have any kind of outreach, in-home outreach program. We do not have [sufficient] funding to provide transportation as it*

is, and we would have a lot of difficulty in providing such an outreach program as well. If there is some in-home outreach it would be to the seniors and through . . . the [Denver] Indian Center.

For those agencies which did provide outreach, the services were limited, and not necessarily focused on American Indians:

[Regarding] Colorado Rehabilitation Services, . . . one of the biggest difficulties is counselor time--being able to go out and do that in-home outreach. One exception is serving the blind and vision impaired. We do that pretty regularly. We have rehabilitation teachers that provide in-home instruction and daily living skills. We have a counselor working with the blind to do in-home outreach. I would say for the most part we don't typically do a lot of in-home outreach unless the person physically can't get to our office.

Denver Options, [serving primarily persons with developmental disabilities], speaking from that point of view, we have maybe 1% of our population out of 1,000 are Native Americans. We have, in a sense, shifted from having people come to our institution setting, we made it more user friendly by doing in-home outreach. . . . There are not going to be new services to people until we raise additional funds or redefine how we do service delivery. . . . We can't serve more than a thousand people right now. The only time you get new people in the system is when somebody moves out, dies, or decides they don't need the services anymore. We have waiting list of 300 people, most of them are transition age, from school to work that we are not providing any services for--not even resource coordination. . . . I hope to learn a lot about how we might outreach more and provide some kind of services. But there's some systematic problems in the developmental disability system in the state that inhibit us from serving people who are not already in that. The whole state has a waiting list of 1,000 people that are not getting any services at all. So if you didn't get in in the '70s and '80s your chances of getting in now are really reduced. That's an issue. . . . We do have two people on the staff who are partially Native American so we have some outreach there, but we're always looking to hire people. We're real committed to diversity.

At least three agencies specifically targeted the American Indian population for outreach and/or service delivery; however, the outreach was either provided on a very limited scale, or had yet to be initiated at the time of the focus group. For example:

Prior to 1993, Eagle Lodge did not have any outreach services available, but we did recently receive a contract through our outpatient component to provide

outreach and interventions, and so we do have basically funding to provide outreach when needed.

We (Indian Education Program) managed to have a volunteer psychologist that's done some home visits until to the point where he felt like he didn't need to go there anymore. And we've also provided tutoring in the home. . . . We don't have staff resources nor the expertise in our staff to handle severe cases.

I did go to the meeting [where research results were presented to local community]. . . . Social Security was there. A couple district managers and I was there. I was just going to come as a regular person, you know, not as a Social Security employee, but in the end I got involved in that aspect too. Found it very interesting that there was so many different things that the Indians were concerned about with the services that we provide, Social Security. So, as it turned out, we were able to get a booth at the pow wow with [the AIRRTC], and from then on it just kind of came naturally that Social Security has a booth there every year now. And that was real good.

Case-Management

Responses by PAC Members

PAC members were generally not aware of agencies with case-management services. One agency provided case-management to people with disabilities who had a vocational goal, but did not focus on American Indians with disabilities:

After the study, we assigned a counselor to the [Denver] Indian Center and one to [Denver] Indian Health [and Family] Services as liaison with them and Rehabilitation Services. [The counselors were] to make a regular appearance in those facilities for taking referrals--this kind of thing. The result was they didn't--or they haven't had very many referrals . . . ; but I don't know the reason totally. . . . We perform a form of case-management in terms of having it being vocationally related. Those services that a person would need in order to get to a level where they could go to work would be provided. Now, that might be any number of services that we provide in terms of physical restoration or mental restoration or assistance with Social Security or Social Services, any of those. . . .

Responses by Consumers

Consumer participants were not aware of any case-management services provided by a service agency. One person stated specifically that there were no such services available. Participants felt that there was a need for case-management efforts, but were unsure as to how such a program could be initiated:

If we took this study here that we're dealing with today, and the information that you have all got from it so far, how could we better improve [the situation]? Like we mentioned now--some of the ladies mentioned that we need our transportation, money for pills, and stuff like that. So, how could we as a community help this thing better? I don't know. I mean, being that you have the study, could you see something in the future for us?

Responses by Service Providers

Denver Options, Eagle Lodge, the Denver Mental Health Corporation, and the Chaplain's Association for Native Americans (CANA) were reported as providing some form of case-management. For example:

You see it within specific agencies such as the Mental Health Corporation, where they have a fairly well-developed case-management program, including often, the use of case-management aides. Sometimes these [aides] are also consumers--[we are] increasing the word consumer in the mental health field to include a person who might traditionally be called a client or a patient--so this is encouraging. However, to the degree which it reaches beyond a particular agency . . . is erratic. Doesn't mean the interest isn't there, but the actuality of [case-management] going beyond agency lines is very problematic. Sometimes it will occur; sometimes that occurrence is somewhat coincidental.

Only Eagle Lodge specifically focused on case-management for American Indians with disabilities, specifically, Indian people with substance abuse disorders. However, the agency representative clearly indicated that these services were not related to the recommendations of the 1990 AIRRTC needs assessment:

We [Eagle Lodge] also employ . . . a case-management system. . . . We do make it part of the process to ensure that [clients] have medical services to include vision, dental, and other types of medical services through local clinics for the indigent. . . . We also hook up clients with voc rehab along the lines of training for jobs and for completion of high school, GED. We also try to see that minor children have adequate health care and that they're receiving their educational needs as well. But this wasn't done as a result of the survey, but this was just something that we put together this year based on a needs assessment--our own needs assessment.

As with outreach services, others had attempted to develop programs in order to better serve Indian people, but without success:

We met with Wallace Coffey after your study was completed and we wanted to start kind of like a mini-contract station here for people who came to the [Denver Indian] Center, but that also just kind of fell by the wayside because there was no cooperation--not just from the Denver Indian Center at that time, but also from our side, from Social Security. So we are trying to take some remedial steps in that direction now.

Vocational Rehabilitation Services

Responses by PAC Members

PAC members agreed that there were no vocational rehabilitation services which focused on the special needs of older American Indians with multiple disabilities. One participant commented there was a blind services program available for elderly persons with visual impairments which offered independent living services. Typically, programs existed for older persons, or for people with disabilities, but not targeted toward the older Indian person with disabilities. Comments included, for example:

*The point is, there is a community center board, there is vocational rehabilitation, there is special education, all of these entities have the legal responsibility to provide those services to anybody that walks in that door. . . . What this thing says to me, "Is there something specific aimed at those groups [an aging work force with multiple disabilities]?" My gut feeling is, "No, there isn't." **If they will come to us, we don't discriminate.** I don't think they have any specific program where they make that special effort. [Emphasis added]*

Are the services available? I would say they're available within the American Indian community. Whether the American Indian community accesses them would be another question. Whether they are sensitive to the needs of the American Indian community is another question. Certainly, they cannot discriminate and not serve American Indians.

I work with the Seniors Incorporated . . . ; it's for the older Americans. They have to be 55 and over and have a limited income. And this is to supplement--whatever they get paid from Seniors Incorporated supplements their income. And I had disabled people working for me, but no more. They can be put in one place for two years and then, we can transfer them over somewhere else.

Responses by Consumers

Consumers stated that they did not know of any vocational rehabilitation service which focused on the special needs of the aging work-force with multiple disabilities. The only related service of they were aware was the senior program at the DIC. One participant noted:

> *I thought here at the Denver Indian Center, they had programs like that [before] . . . . Why do they all fall down? I mean, that's the problem that needs to be addressed here. We need to find out why they never keep going. There's a lot of things they could do. There's a lot of things we could do as a community. . . . There's all the Indian native crafts that we can do and all these things. This all happened in this community building, but it all seems to stop. I don't know why.*

Consumer participants felt that there was a need for establishing a vocational program in Denver to assist older Indians with disabilities:

> *Have some kind of a vocational program established in Denver--these older people that wanted to do something, handicapped people that want to do something--that would do something for them.*
>
> *Maybe if we have established a program here; maybe within this senior citizen program. Have somebody that's knowledgeable obtaining funds from other organizations [so] that we might be able to set up something here for our own people. That might be something that we might look into.*

Responses by Service Providers

None of the service providers knew of vocational rehabilitation services which focused on the aging work-force in the Indian community. One participant pointed to the "turn over" of leadership in Denver service agencies, as well as the lack of communication among agencies, as reasons for the lack of specialized services:

> *I know there are issues related to the aging work force [for] people with developmental disabilities. There is an interest in providing more service. There is resistance of a lot of provider agencies to do so--that means they have to experience a systems change, which we're finding a little stressful for providers in Denver. . . . Give you an example. Denver Board [serving persons with developmental disabilities], had four executive directors in five years. There is no way that you can provide quality services when your management turns over that quickly. . . . Talk about innovative programs--it isn't going to happen. So, I think management is a real issue . . . [and] the*

fragmentation of the community of disabilities is a tremendous barrier. We're duplicating services left and right; we're not talking to each other. I think those are significant issues [that] certainly impact our lobbying ability for increased funding.

I'm not aware of any VR [vocational rehabilitation] services available for older Americans. I'm not aware of any at all. We use state VR, but this is for everybody. I'm not aware of any special needs services.

Employment Opportunities

Responses by PAC Members

PAC members were aware of programs which worked to increase employment opportunities for American Indians, but not for American Indians with disabilities. In one case, a program which targeted American Indians in general, actually placed an American Indian with a disability:

. . . through the Federal American Indian Program Council and a special emphasis committee, we have an Indian person that was employed through a work study program or stay-in-school program. . . . There was a special effort to find an American Indian and that American Indian happened to have a disability. . . . [Through this program], you have an opportunity to work for the Federal Government. You aren't really a permanent full-time employee; you are part-time, and you are only there because you're in school. If you quit school, you're out of the program. It will give you an opportunity to see what career service would be like--civil service. . . . [The experience is] entry level, mostly clerical. . . . The HHS, U.S. Department of Health and Human Services, has a special emphasis committee which has been entitled Native American Program Committee, and through that we became aware--our committee received an orientation from personnel of employment opportunities available for youth. . . . We had an orientation to all the options that were available, and through that we invited the Denver Indian Center . . . to our building, and the representative came and through that we worked to let them know of employment opportunities. . . . My point is, the Native American community did receive special orientation to find out about employment opportunities and I think in this case it was a special effort.

. . . Denver Indian Center has JTPA . . . and that has been a very instrumental project in terms of the training and job placement of American Indians in this community. I don't know what the numbers are like, but I do know that . . . there are active efforts right now that are addressing the work force.

One agency representative referred to the fact that his agency had made a grant

available for which American Indian service providers could apply:

> *I would respond to the question in the same manner as I did, I think, to the first one where we had attempted with the [announcement of the] establishment grant to employ aides for outreach and kind of liaison, as one of those potential employment opportunities.*

Responses by Consumers

In general, consumers were not aware of any efforts to increase employment opportunities for American Indians with disabilities. One participant stated that the agency, Seniors Incorporated, had assisted him with finding a job; however, he noted that the organization was "dwindling down to nothing, now." A major reason for reduced services, according to the consumer was "there's a lot of problems with funding." Another consumer described her experiences:

> *There is a kind of rehabilitation through Social Services in Denver. . . . I went over there once and they took intake on me, and first, they said they have to determine if I was disabled before they could help me. And nothing ever came up with it. Because if they determined if I was disabled, they were going to try and find me a job I could handle--send me for some kind of training or something. But nothing ever came of it. So, I don't know what happened.*

> *I don't see any improvement in the employment part unless you go to the State for unemployment. I don't know of any.*

Responses by Service Providers

Two participants discussed the efforts their respective agencies had taken to increase employment opportunities for American Indians; neither specifically targeted Indian people with disabilities:

> *Denver Mobility or Metro Mobility, we made a big effort last year to interest Native Americans in coming to our company to seek jobs because we hired three people last year. We had two individuals who did come in; we did hire them. But, we are very interested in having more Native Americans. We put out the word, but we really have not had very many come in and apply. We [Vocational Rehabilitation] tried to do some pretty extensive outreach in terms of employment within State Rehab. We do really believe that's a future need or current need in terms of trying to recruit qualified Native Americans to work with Native Americans in the state. And we have tried to do some pretty extensive outreach--go through universities, or programs such as this one, trying to recruit individuals, and it has not been very responsive in terms of developing people.*

Self-advocacy Efforts

Responses by PAC Members

PAC members felt there had been no special efforts made among American Indians with disabilities to come together as a "community" and engage in self-advocacy. One participant expressed the belief that Indian people with disabilities were protected by family support, and did not feel the need to come together as a "community." Others suggested that advocacy efforts might be initiated through interested agencies, as well as persons *without* disabilities. Comments included, for example:

> *Historically, traditionally, in the Indian community, many of the people that have disabilities tend to get absorbed in the family. You know, the family takes them and kind of keeps them quiet. It is a quiet issue, nobody really talks about it. . . . The bigger issue is, we have few in Indian leadership and those individuals in leadership wear so many different hats that the demands are just far greater than, you know, the supply. . . . We want very much to make sure we don't force our leaders out because of burnout--because of frustration levels. That's the bigger issue.*

> *To my knowledge, I don't believe there's any effort made to unite. . . . I certainly think the time is right that there should be some effort now, being that there is no agency presently doing it. I think that it would be a good idea to initiate something at this time, if we would be able to.*

> *. . . [The question reads], "what efforts, if any, were made by American Indians with disabilities," and I'm relating experiences in the Hispanic community. Whenever they say disabled Hispanics, that narrows--we are having problems just getting Hispanics involved in discussing this thing. So that I hope we don't say that it has to be [only] the disabled themselves. . . . My argument with that, first of all, we have a hell of a time just identifying Indians, or Hispanics, or Blacks that just want to serve [on boards], whether they are able-bodied or not. . . .*

Responses by Consumers

Participants in the focus group did not know of any efforts among consumers in the community to unite and engage in self-advocacy. Comments included: "We were never notified of any [meeting]. . . ;" and "I didn't know where to unite."

Responses by Service Providers

Service providers were not aware of any efforts being made by consumers to engage in self-advocacy; however, as with the PAC members, service providers

suggested that the initiation of advocacy efforts should come from service agencies:

> *I think definitely that an effort should be undertaken again to unite the community. . . . It's incumbent on the service providers to realize we're here for the community and we are here to advocate for our community. And because we are service providers and we are professionals, we need to realize the needs of the community. I think that it is also a responsibility of the community as individuals to make their needs known and come to the service providers and say these are our needs that are being unfulfilled, how can you help us? So, it is a dual responsibility. But, I think we need to take the lead, we being the service providers, because I would say, if you would look at the Native American adult population here in Denver, I would say, at least 50% of our population will come under the heading of disability--at least having one disability. These are barriers to employment, to adequate housing. And if we can't meet these needs, these barriers still exist. So, it is incumbent upon us to work together again.*

> *I have not seen any effort to unite the community of American Indians with disabilities, but I do think . . . through the Senior Center here, [there has been] an effort to unite the seniors and to try to get transportation for the seniors, some of them with disabilities.*

Assistance with "Community-building Efforts"

Responses by PAC Members

PAC members were aware of service agencies which assisted American Indians with "community-building efforts." However, these efforts were not targeted toward American Indians with disabilities; nor did they include specific information in the area of disability rights, for example, the Americans with Disabilities Act:

> *The Title V [education] program has made some rather hallmark efforts to gather the community together to include the child, the student, as well as the family members.*

> *We do something here [at the DIC] every Tuesday night--try to bring the seniors here. Tonight, they are going to have a dinner, like an Easter dinner and dye their eggs. . . .*

One participant suggested that some individuals who needed help did not come to agencies; they went to "one another and supported one another." Specifically:

> *This is what happened early in special education. They didn't have parents pulling together until they formed the PTO, I believe it was, to bring the*

parties together--to say, you know, we share this problem--let's see if we can find a solution. And it was the support of the parents for each other, I think, that really took the special education program and ran with it.

However, PAC members also expressed concern with the changing values they were witness to in the urban Indian community:

There's so many young parents, single parents having to take care of one or two children, sometimes three, and it is hard for them. I believe, that traditionally . . . the elders taught their children what to do and how to live and there was a lot of respect. But, that's no more. You know, these Native American children don't respect anything or anyone anymore. And it's hard. . . .

There was concern that service agencies did not have human and financial resources allocated specifically for assisting "community building efforts" and "there are few [Indian] leaders and those who are leaders are getting burned out because everybody wants them to be on a committee." While there were few human or fiscal resources, the consensus among the PAC appeared to be that any community building efforts would have to begin with the young and with the family. For example:

I think the whole community is doing something like, you know, starting with the young people and involving parents of the youngsters and working this way because of what is happening now. You know, people are--people are bad; there are so many dropouts, especially with American Indians--teenage pregnancy, gang members. I think that's the only way we can do something is start with the young, with the parents, also. . . .

Responses by Consumers

All but one consumer stated that they were unaware of any assistance provided through service agencies for the community building efforts of Indian people with disabilities. One participant stated: "There's been a few, but I can't say just what they were."

Responses by Service Providers

Attempts made by three agencies, that is, the seniors' program at the Denver Indian Center, the Denver Public Schools' Indian Education Program, and Denver Options [serving primarily persons with developmental disabilities], were cited by participants as having provided assistance for the community building efforts.

Much of the focus group discussion centered on the problems of personnel, funding, and the lack of coordination among service agencies which might provide such assistance:

> *One thing that concerns me, there still seems to be some kind of barrier to communication that prevents us from getting together. I know with regard to the school system, you know, there are a couple of things that rehab services is quite involved in right now. . . . [But], there hasn't been any further communication or discussion as to what the students' needs are. This time of year we typically are taking referrals on students for the Fall. . . . I think there's some things kind of in place, but we're not communicating or working together to make it work for all of us. . . . You know, we do have [VR] counselors that go out into the school, meet with teachers, meet with parents, but we're not getting asked back, and I'm not sure why.*
>
> *. . . I found as a parent with a child with disabilities--the systems really don't understand my needs well and I had to learn that the hard way. . . . And my daughter has severe physical disabilities. We had to raise money for our wheelchairs. . . . I've had to raise $60,000 on my own to provide for her needs. We don't teach people how to do that.*
>
> *I'm very interested in outreach. However, we do not have funds for so many populations. . . . I'm saying unless people are elderly, it's very difficult . . . to find funding.*

Participants also considered ways of resolving these problems by giving examples of programs that were working to build community and/or examples of potential solutions:

> *I wanted to mention that with the Denver Public Schools, they have allowed us to create focus schools. And what that means is we'll be able to provide our parents with the option of sending their children to fewer schools rather than 114 schools. And in the Fall of this coming year, we'll have the elementary through the 12th grade together, finally. . . . So, we have been asking for about a year and a half, to different groups, "What services can you provide to these children and the families?" And a lot of organizations are going to try to ask for input and try to come up with some good answers. We have a day scheduled, May 6th, and all of the focus schools will be represented and describing what kind of programs are in their building for parents to consider whether or not to send their children there. And then, organizations are coming over to ask "what kind of services do you want from our organization?" So we are looking forward to that exchange so that we can become prepared in the Fall on how to provide services.*

One of our [Denver Options] training grants, because they are focused on training people with disabilities, and addressing minority issues, we held--and it was geared toward Hispanic communities--what we call a "community connections" two-day forum. We recruited people from all the systems, from the legislature to Social Services to VR to everybody. We tried to find people who were Hispanic who worked in the system. We recruited people from across the state to come and spend time on two days. . . . We tried to train them on the systems so they could go back to their communities and, you know, how to activate, who to talk to and be connected with. . . . We got excellent response.

. . . What we need in this community is a tremendous coordination of services here. And I think it is incumbent upon the Indian community to establish the responsibility and carry out that coordination of services. . . .

. . . And I think together we could leverage a lot of services for Native Americans, especially if we could identify the populations that are in most critical need, the seniors who have disabilities, who are isolated in their homes, or young people who need to get out to social events even. I don't know. What can we do to pull people together?

In [a recent] RFP (request for proposals) there's a statement . . . that says: "How are you addressing the issue of delivering services to severely disabled individuals who happen to also be minorities?" Since this is required in our grants, . . . why aren't we hitting those various grant-funded programs and finding out what they are doing? If they're not doing anything, you have a good place to start moving. We're either lying like sin on what we're doing or something.

Programs with Emphasis on "Health and Wellness"

Responses by PAC Members

Regarding programs that serve Indian people and that focus on the "health and wellness" aspects of disability, PAC members noted that the Denver Indian Health and Family Services (DIHFS), which was "one of the primary agencies that supported the [1990 research] effort, has encountered very serious financial problems . . . and severely limited its services." For example, the comment was made:

There presently isn't any health and wellness programs that I know of that are going on. They [DIHFS] did away with the clinic and community health services. . . . Community health services--that was an outreach [program].

Responses by Consumers

Conversely, consumers referred to a wellness program offered by DIHFS:

We have a wellness program. We have that exercise program in the afternoons.

Responses by Service Providers

There were no comments by service providers as regards the availability of health and wellness programs.

Efforts to Train, Hire, and Retain Indian Personnel

Responses by PAC Members

In regard to efforts which had been taken by service agencies in Denver to train, hire, and retain American Indian personnel to serve American Indians with disabilities, PAC members referred to the efforts of Social Security and the Federal American Indian Program Council (FAIPC). However, it was pointed out that Social Security was focusing its efforts primarily on reservations versus the Denver-metro area, and as stated earlier, the FAIPC was focused on the recruitment of all American Indians, regardless of disability status. Comments included:

The only one I can think of is SSI. . . . It is in the process of--and this one is not . . . in the Denver Metro area--[it is] occurring on reservations within Region 8, which includes [for example], South Dakota, Colorado. But, there is a specific outreach effort to hire American Indians.

. . . the Federal American Indian Program Council, and part of its mission or goal is to increase the employment of American Indians in the Federal Government. . . . One of the outcomes of the last meeting was to have more American Indians employed in order to have the Indian community relate to the service provider.

Concern was expressed that recruitment and special program efforts were focused on Indian people on the reservations and not in urban areas:

We concentrated in providing monies to develop rehabilitation programs on the reservation, but not on urban areas. Because the expectation, the mentality is that, those [urban Indian] people can go to VR, go to DD, go to the general hospital right there in the [urban] community. . . . You know, that's fine if we are doing it on the reservation, but, we have the same need here in the Denver-metro area where we have 20, [or] 21,000 Native Americans.

. . . maybe because there is so much more media attention given to the needs of reservation Indians as opposed to urban Indians; maybe there's thinking that attention needed to be focused there.

One agency representative reported that VR employed a Native American "home teacher" as well as two other Indian people; he was not sure of their specific jobs. He expressed frustration that, as reported earlier, there had been no response to VR efforts to recruit American Indians into employment through a mail campaign:

. . . Our problem, when we could fill vacancies, we were actively recruiting and we sent out many, many letters asking for referrals of qualified staff. We did not receive one response from any of the places we sent those, and those were to universities, to reservations, to community colleges, to a lot of different places.

Responses by Consumers

Participants were not aware of any efforts taken by service agencies to hire, to train, and/or retain Indian personnel. Reference was made to the experience of one participant who encountered an American Indian staff person working in a non-Indian agency; the consumer expressed the irony of an Indian person serving primarily non-Indians when the need for Indian people to serve Indian people was so great. He commented:

She's real educated. I don't know if she was brought up on the reservation or not, but she's Navajo. . . . She's never been to the March pow wow before and I told her about that for the first time.

Responses by Service Providers

The comment was made that the "Social Security Administration (SSA) has always tried to recruit American Indians;" however, it was reported that the recruitment efforts by SSA have not been particularly successful:

During that time in 1989 and '90 my acting district manger at that time wrote to every single college and university across the nation who had a large Indian population . . . and asked it they would be willing to work for Social Security. I can't remember how many schools--like 20 or 25 schools. Not one response. No one signed up. . . . [Now] we're trying to get President Clinton to issue an executive order that there will be more American Indians in the Federal work force. . . . I think with the few of us who are with the Federal government are really pushing it. . . . So we do need the support of the

Indian community. . . . It is important. It needs to be done as soon as possible. So those are our efforts.

Participants reported that employees of DIHFS were actively involved with the American Indian Mental Health Task Force, which addressed the recruitment, retention and training of Indian professionals. The recruiting efforts of the Center for Technical Assistance and Training at the University of Northern Colorado were also noted. Comments included:

We were able to get $4,000 this year discretionary money toward this specific task.

We have money set aside for recruitment of minorities and generalized staff training programs.

However, participants were more aware of the problems associated with recruiting American Indians as personnel in service agencies than they were successful efforts:

One individual was reluctant to leave his state and the reservation. I think there's some conflict there that might be worth exploring. There's mixed loyalties. Recruiting people through the university, they feel like they need to go back to their community rather than participate in ours. We're in a different focus in the urban setting.

. . . You can't get them [in college] unless they get out of high school.

. . . Why are we not graduating many Indian kids out of high school? What's going on? Is it urban dilemma or reservation dilemma?

I think that one of the biggest encumbrances to people being available for training and employment are transportation and child care issues. If we cannot address those, if we can't get the people out of their homes, they can't get trained, they can't go to school, can't go to work--we don't have those resources either. It's a multifaceted problem that has to be addressed.

Significance of the Issues

The PI acknowledged the concerns presented above regarding transportation and child care, limited human and fiscal resources, and reservation versus urban focus. Thus the question was raised regarding the relevance of focusing on disability issues within the American Indian community: "We've been trying to force the

issue--force the focus group discussion to center on Indian people *with disabilities* and their needs. So the question now on the table is, "Is this even the right question to be asking? . . . Are there other issues that we need to be addressing . . . ?"

Responses by PAC Members

PAC members commented, for example:

> *Yeah, I care. I care about it a lot. You know--personal and professional reasons. Our '92 (Rehabilitation Act) amendments require a degree of outreach to minority groups. So, that's one reason that I care about it. I guess the main reason I care about it is the reason I came into the profession in the first place, that was to work with people who needed assistance of some kind from a rehabilitation perspective. . . . We can diagnose things to death and we can identify issues to death, and unless we establish some means of dealing with them, then, why do it? And I guess, I would like to see questions asked about how can we best do something about it and who--you know, who, what, why, when, kinds of questions to be answered to do that. . . . I would like to put my energy into that kind of an approach.*

> *Yes, I care. I care very deeply or I wouldn't be here. I have been with the agency, especially the Indian agency, and I don't feel that there has been enough energy put into it. And I think there has to be a lot of "whys" asked and what's going to be done and whatever. And I think we have to move on. Certainly, I think the concern is there if we can just generate enough concern and certainly energy, both in the Indian community and otherwise.*

Responses by Consumers

Participants expressed the need for a self-advocacy group as well as a support group. They posed as a dilemma the need to organize a grassroots movement, and also the need for a leader (see below, *Responsibility for Action*, p. 39).

Responses by Service Providers

Participants noted that often "outside" groups attempted to enter American Indian communities and determine their needs versus allowing community members to make those determinations. Comments included, for example:

> *. . . We from the outside go in and try to find out what they need rather than letting the group determine what they need and come and say, "Can you provide this? This is what we need." We come in with our package, try to sell it; [if] they don't need it, we don't ask anything else. We need to find out what the needs are, then [ask], "Can we address those needs?"*

As an alternative practice to "outside" assessment, the representative from the Denver Public Schools' Indian Education Program reported that program staff conduct a survey every year to document needs.

Participants discussed the lack of congruency between consumer expectations and the services that are available. Lack of follow-through was identified as a problem, as was the time consumers spent waiting for services. For example:

> *I think also people with disabilities, in my experience, often lose hope for themselves. And I think when you go to a planning approach, you help people create new dreams. At the onset of the disability, you have to re-configure yourself, reinvent yourself. I think some people lose hope and they withdraw and kind of don't get back into life in the way we would hope people would in a more productive way that contributes to the community. And I think that's an area that people need to spend time in.*

> *. . . There's such a delay in waiting for services, like with voc rehab, with some of our people. Trying to get them jobs once they go through the program--takes them three or four months to go through the process. If I can't get somebody into training within two weeks after our program, I lose them. They're out on the street. Whose fault is that? I'm not trying to lay blame.*

Role of the University-based Research Team

Responses by PAC Members

PAC members generally agreed that university-based researchers should return to a community after a needs assessment is completed and facilitate any actions needed in order to implement the study's recommendations. Participants pointed to the shortage of American Indian leaders and agencies in Denver with the resources to implement recommendations. However, as one participant noted, the research team should not come to the community "as an entity to come in and save the community, but more in a capacity to facilitate, help the community help themselves and spearhead it and organize it."

Participants believed that the university-based research team had the resources to: (a) bring consumers and service providers together, (b) work with support groups, (c) provide documentation to government agencies regarding the needs of American Indians with disabilities, and (d) facilitate the mobilization of an action group. For example:

I think we talked about a support group and that might be one thing that wouldn't take any money, other than the building; identify the people and invite them.

I don't think that the research team, or entity, . . . the Research and Training Center at Northern Arizona University, should just go back and write this thing up and send it back to Denver. That's only part. I think the other part should be infusion into the federal government system through NIDRR (National Institute on Disability and Rehabilitation Research). Here are some findings--here are some recommendations . . . ; you can give all that information to the community, [but] if we don't have the resources to make it happen, it doesn't happen. What should happen is this thing should go back to NIDRR, your funding agency, who in turn, can make something happen with RSA and . . . lay that on the state agencies, whoever has those agencies, and force them to do some of those things. I think if it just comes back to the community, we can all agree that, yeah, those are good findings, and yes, we need to do those things. . . . Hopefully, somebody would wrap that [the final report] up in a nice little ribbon and personally deliver it to Ben Nighthorse Campbell so he would begin to feel that thing and see that thing and assign some of his staff and look at some of those things. . . .

I think it should be [community] people who are--who have interest to pull it together. But, on the other hand, I have concerns. . . . If you don't have the resources, what can you do with a lot of interest and no money? So, I have somewhat mixed feelings because I'm also concerned about if you leave too much to the government you lose the perspective and it might become a numbers' game. So, I think maybe a combination [of the university plus the community]. . . . Because everyone else has their own full-time job to do. . . . I would leave the action plan to the community and the development--the university could help. I'd be cautious of how it should be worded, so [offers of assistance are] not misinterpreted as paternalistic, or in that vein.

I have been involved in focus groups in the past here in the Denver community with focus on American Indian families, and there was in fact some very sincere individuals in those groups and we kept meeting, and we kept talking, and we kept inviting guests, and it seems we weren't able to do anything until we had some support from the university. And there was some clout that was given, or some credibility that was given to our task force group at that time that enabled us to have a greater voice. So, I would say, you know, not necessarily abandon the project, but allow us that alliance with the university.

Additionally, participants believed that the university-based research team could: (a) research and identify for the local community "who has the capacity within the community to affect change" and (b) "take a look at the various pieces of

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legislation and try to provide assistance to the local communities to understand what the potential of the legislation is." Specific comments included, for example:

> *I don't know if it's feasible--if the research team would look at organizations that have the service to American Indians in mind, or some that are just disabilities in general, to identify those groups, agencies--whatever they might be, entrepreneurs--whoever they might be, to determine whether or not they would have the resources. . . . I don't know if self-determination is still a buzz word or not, but we talk about self-determination and then don't provide any resources to get it done. I mean, that doesn't seem right.*

> *[Legislation] says the state agency now has to say here is an underserved population and this is how we're going to reach that community. I'm certain they're going to write something and they're going to think it's correct. What I would like to see is an outside group to take a look and see whether what they're proposing really jibes with what we know about the community. . . . Some people in the community are too busy taking care of business. You know, they don't have time to think about potentials.*

Responses by Consumers

Consumers expressed unanimous agreement that the university-based research team should be in contact with the community even after submitting a final written report of the research results--the university research team should work with the community in solving any problems identified through the research. Comments included, for example:

> *I think they should be involved--just to be there to help and supervise; you know, to see it's going the right direction.*

> *I think it should be followed through and some kind of action be done; otherwise, it's just a waste of time. They will say we took the survey in Denver; they said this and let it go. So, I think it should be followed through--followed through to get funding or a center for disabled [persons] or a program.*

> *So with the survey that you took us three years ago, the information that you took back, you put together something and give it to the people involved so that we can all take advantage of it. And you did do that and none of us heard about none of this.*

> *We should all work together to get it moving. Otherwise, it will just fall apart.*

The disabled, plus the community plus, whatever support we can get.

Responses by Service Providers

One interpretation of the role of the university-based research team was summarized as the three "A's":

> *Action, activism, and advocacy. They're not the same. [To] some degree interlinked, but they're not the same. Action can be just as you've done to appropriately initially share the report. And if that's part of the contract, and you shared it, you completed the action step that was necessary. Activism goes a little beyond that. . . ; it involves people and perhaps the follow-through. And advocacy can include, of course, consumers and others working hand in hand with those who aren't consumers. . . . The universities can help in all those ways.*

One service provider commented that it would be helpful if the university research team would not only provide the results of their work, but then explain their conclusions in such a way that people are "walked through it." Specifically:

> *Sometimes, on our part, we don't take the initiative to read [a research report] and try to understand it ourselves. But, it's appreciated when groups do share their conclusions, and do that is such a way that it's informal and we're able to ask [questions].*

Similarly, the need for training following the research was identified:

> *In other words, just do the research and pass out the information . . . nobody reads it, or if they read it, they can't understand it, or they're too busy to implement it, or they can't implement it. I think the RTCs (research and training centers), using the TC (training center), needs to go out, and if there's anything to be trained in, train them. . . . If the research says nothing, you don't have to worry. Two components, research and training. I think most RTCs tend to do the research and forget the training. . . .*

A representative from the Center for Technical Assistance and Training spoke of their management mentoring program:

> *That's how this management program came along--we could give people technology, but we couldn't change the system. They were trying to do bottom-up change, but it was difficult. So we found that we needed to be mentors. . . . Why aren't people [creating change]? Because people need coaches--that's the conclusion we came to. People need mentoring, they need coaching--organizations need coaches. . . . I think that, you know, it takes a lot*

of courage, it takes a lot of focus to deal with information such as [the research report], and then figure out how to implement it. You need some technical assistance around that sometimes.

Thus service providers generally agreed that the university should provide assistance with problem resolution after problem identification:

I would think if you're going to spend a lot of time and effort and money to go ahead and do some research you would follow-up with some plans to implement some type of a plan. I think it's been known for a long time there were services that are needed here for those with disabilities. . . . We know there are problems, but how can we fix these problems? . . . It's vital for our community to know how can we deal with our problems here. You know, I would hope that you would be able to provide this training, provide these insights, provide a mentoring program, help us see how we can . . . solve these problems--how do we work towards obtaining these goals?

O and M, operation and maintenance, after a project is implemented, as we all know, is essential. . . . We have to have O and M built in upfront on projects like this too. . . . It's a part of what we need to do system-wide and to involve qualified people like NAU and others. If we put O and M as some kind of fancy exotic extra thing that maybe we'll do if we have money, we've missed the boat. O and M is equally important as the actual project study, as the actual project implementation. And O and M in our case here isn't, of course water or systems maintenance; in this case, it's what things we just mentioned a few moments ago--follow-up, evaluation, training--that's our kind of O and M.

Responsibility for Action

Responses by PAC Members

PAC members discussed the necessity of having both strong agency leadership, as well as informed leadership, if a community was to take action regarding needed changes in service delivery:

If there's money involved, we're going to have to have an established organization. . . . If there is money involved, and I hope there is, if you want to get things, it takes money. . . . Certainly, you are going to have to have a leader in whatever organization is chosen to head the group. And hopefully, one of them will pick up the needs of the grassroots people and say, "Hey, let's do something."

Participants returned to the issue reported earlier regarding the shortage of Indian leadership in the Denver-metro area:

. . . the way the Southern Ute and the Ute Mountain Ute reservations went about getting their Section 130 program was as the result of an Indian leader taking the bull by the horns and going after it. . . . And so it was a result of a strong Indian leader developing that grassroots effort. . . . So maybe we do need to have a strong leader to step forward [now]. Does that Indian leader have to be an Indian? Could it be a university?

I was going to say it is much easier for the reservation, for the tribal organizations to have a leader. Right now, we don't have a leader in Denver. I can't see anyone being a leader for the Indian community. . . . Maybe there's some people that they are saying they are the leader of the community. No one is recognizing anyone.

It's a possibility [for a non-Indian to be the leader]. If you have someone who's interested enough to take the ball and run with it and they're sincere. I mean, let's face it. If the need is there and you find someone that is sincere and is going to do something with it, and provide services, you know, who cares, if that person is sincere enough.

Responses by Consumers

Consumers expressed both the need to form a grassroots movement to ensure that their needs were met, as well as the need to have a leader and agency support:

We go back to the same thing. We need a group. We need a location. We need support people, so we can keep track of all these things that we need.

We need a good leader.

Before you start anything, you have to have funding. I don't think we can get any funding.

It takes a person to know how to start--know how to bring in the money and get people to help them, you know. If a person is working like that, I think everybody can be together and help this person to do it--not just that one person. We should help out with them and get everything going--whatever we want done. If we don't get together, it's not going to get done.

. . . if we are going to get together here and get an agency to work with the Indians here in Denver, couldn't we find ways to go back into our own tribe and see if their public service could help us get some kind of an agency for us here, and from the State of Colorado get our senators and representative . . . . Can they--can we make a proposal or something through them and have them work and get some government funding for our group here?

Responses by Service Providers

In terms of effecting change, service providers focused on the need to build relationships with grassroots leaders, emphasizing that "telling" the research results may be less productive than "consulting people and sharing information." One participant commented: "Change happens through building relationships." The importance of building relationships was highlighted given the lack of trust of non-Indian people by Indian people, according to one service provider:

> *I might add that that's been a problem historically with Indian people--that it's difficult to trust particularly non-Indian people and non-Indian service delivery systems.*

Role of American Indian Community

Responses by PAC Members

Participants were asked to discuss the extent to which a unified Indian community existed in Denver and to what extent the community was willing to advocate for Indian people with disabilities. PAC members felt that unity in *any* community was difficult to achieve--given differences of opinion. According to one participant, Indian people come together depending on the cause:

> *Perhaps, this is one of the causes that will bring unity back. . . . It doesn't necessarily have to be Indian. Go back to the grassroots--get strong enough people within this community, whether they be disabled or not. People that are concerned, I think, can do it.*

PAC members believed that the Indian community was willing to advocate for Indian people with disabilities:

> *I think there's an interest. There seems to be little sprouts here and there that pop up, but, everyone popping up together, no.*

> *. . . if we were able to identify someone in the Indian community to work with a state agency that has already expressed interest in wanting to put together some kind of proposal to hire staff, to deliver services to the disabled. . . . And don't take trying to provide [all] services for the disabled Native American--that's too big. Let's start with . . . employment or vocational needs and from there you'll begin to get the big picture.*

Responses by Consumers

Consumers expressed doubt that there was a unified community "all put

together nicely in a package, everybody working together" that was willing to advocate for Indian people with disabilities. One participant commented: "Dream on." Ms. Vera Mitchell, who co-moderated the consumer focus group meeting, clarified the question by asking: "Do we have a common cause to become unified, to pursue an answer to whatever we're working with now? It's not like going out and saving the whales, it's saving us."

Participants agreed that there was a common cause for people with disabilities to unify and self-advocate. The consensus of the group appeared to be expressed by a consumer who stated:

> *I think that we should be involved with our own problem and we should be our own bosses and stuff like that. That's the way it has to be run. You sent that [research report] to the head office; it stopped--got lost in File 13 or whatever.*

Responses by Service Providers

Inadvertently, this question was not asked of the service providers.

Linkages Among Service Providers

Focus group participants were asked to identify the specific steps which should be taken in order to maximize linkages among Denver service agencies which served Indian people.

Responses by PAC Members

PAC members discussed that a first step would involve establishing a network of service providers interested in serving American Indians with disabilities:

> *Maybe a group of several networks that somehow coalesce through leadership down the road. . . . There may be a network for seniors or elders, as you say, and that's another little network. Somebody leads each of those little networks. So that eventually, you know, if you know about the other network you can--leader can talk to leader, if you will, and amongst them maybe they can find one to lead all the networks.*

Participants also expressed concern that federal monies were spent primarily on reservations; it was felt that similar funds should be available to urban Indian programs too:

For example, the argument that's made why they don't have Section 130 projects in the urban area is because the state agency gets money based on a per capita basis and Indians are counted in that per capita count and [VR] gets money on behalf of those individuals. All I'm saying is we have to find a way to be able to say if the agency is not effective in reaching that community with resources they're already getting to serve part of that community--we need to find that mechanism, part of that could be using 110 money, which is the money that's used to serve any disabled individual in the community. Now . . . we take some of that money and find an entity in the community that could do the same thing the state agency is supposed to do--hire an outreach worker. . . .

Responses by Consumers

Consumer participants suggested that service providers should organize a meeting and communicate face-to-face with American Indians with disabilities:

Set up a meeting I think is the first thing. With the agencies . . . whoever can come. [We] need to find out what's possible.

One participant emphasized, "[With] more people behind the community, you would have that much more power."

Responses by Service Providers

Service providers suggested that the steps needed in order to maximize linkages included identifying relevant agencies or service providers and their contributions to serving Indian people with disabilities, then sharing this information. As one participant stated:

It's incumbent upon the service providers to become aware of all of the services that are available so they can disseminate the information. . . . We need to start today--like what we're doing right here, meeting and finding out what services are available and identifying services that are not being addressed and then trying to seek what resources are available. Basically utilize information that you have here and try to obtain the answers.

Additional Questions Specific to Consumers

Consumers were asked to identify **any problems which they may have encountered when applying for services** during the past three years [since the 1990 needs assessment], as well as to describe **any services which they had needed, but did not receive**. Problems consumers reported included: (a) lack of transportation for

getting to a hospital to pick up medication; (b) difficulties of using public transportation (city buses) for older people with disabilities; (c) concerns regarding the services of Denver's accessible transportation; for example, one person reported that the service arrived two hours late for an appointment; (d) lack of clarity regarding the rules of Social Security; (e) lack of information about available resources or services; and (f) lack of access to dental and/or medical services, for example, the "two years waiting" involved in accessing dental services. One participant stated that she needed day-care services for her sister--specifically one which would accept Medicaid.

Comments regarding transportation included:

We don't have the transportation [to take advantage of available services].

[We need] some form of transportation, so people won't have such a terrible time getting to and from their appointments and picking up medication and stuff like that.

I dealt with the [Denver] Mobility at one time and I didn't have no way of going to the dentist and I called them up and asked them ahead of time--see if I could make an appointment for them to pick me up. And after I got through talking to one person and they told me I had to pay $20, I said, "$20 for one trip? Forget it, I'm not that rich. . . ." So I cut that off. So, I never called them anymore to pick me up and take me to the doctor or anything.

It's really hard to get to the [Indian] Center on the bus. Lot of us ride the bus. Very hard for me to get to the Center anyway. You have to walk quite a ways to the bus and from the bus. . . . I think, it's what, three or four blocks.

Comments regarding access to dental or medical care, included, for example:

I wanted to ask, what about for that dentist as far as the handicapped people? My son [who has epilepsy], he's on SSI; most places they don't have anything for dental service under SSI unless they're under 21. We had a hard time getting him into the dentist and we can't even put him on our insurance. [The waiting list at Denver General Medical Center] is at least two years long. He had a jaw correction; he has pins in his jaw, and when he has a dental problem, he has to have it. So, we have a lot of problems. And you know, they changed the staff [at Denver General] and before that it was easier to get in. . . . Now I got him under the handicapped, but it's at least about two years long, two years wait. We don't know what we're supposed to do in the meantime. . . .

I think if the Health Board was still open like it used to be, all our Indian community people could go over there and get medication and it would be a lot of help to the elderlies.

Comments regarding access to employment or vocational training, included, for example:

What he is saying, you know, he tried to work and he couldn't do it. He's an epileptic, he has seizures. When he has a seizure, they let him go. He's tried so many places and he can't. And he gets all frustrated because he can't have a job and live like normal people, working all the time like his brother and sister and his dad. . . . And what he is saying is, why can't the handicapped people have a job. . . ?

I need some training and I feel like--I feel foolish asking for training at my age. I can do bookkeeping, but I can do bookkeeping without the computers. But, I do need the computer training because . . . And some definite training on some definite trade I need very badly because like I been doing this bookkeeping down there, but it's been dwindling off, dwindling off . . .

In regard to childcare, one participant commented:

I had a problem with something like that. Another reason that I haven't really dug into this schooling issue is because I have a grandson at home who is terminally ill and I have to have someone to help me to plan when I can go to school . . . .

Consumers agreed to the **need for a support group**. One person commented:

I think it would be nice, because I have a handicapped granddaughter and I worked with her all her life and I know her condition and I know how to work with her, but now she can do a lot of things on her own.

Consumers demonstrated that, as individuals, each was aware of information which might be of assistance to others in the group. For example, one participant in the consumer focus group informed the group that Denver General and the University Hospital had a "voucher" transportation system: if it was late at night, if the consumer was a "special needs patient" and if the consumer could not afford transportation fare, the hospital arranged for transport through the voucher system. Participants remarked that they had not known of this resource.

Consumers were asked **to what extent they sought and/or obtained services from a non-Indian agency**. One person referred to a day-care center where she

obtained services. Another person stated that he was registered with the "ABCD Trial" of the Colorado Prevention Center:

> *You're a guinea pig when you go there. They try different things on you, different medicines and stuff. Like I got a little high blood pressure. I go to this place and they give me different pills and I go in every week for different kinds of tests. The medication is all free. If you have to go to the hospital for anything, that's free. . . . There's a lot of programs out there that a guy can investigate and use.*

One consumer shared how she was able to access SSI:

> *I tried to get Social Security. I kept getting denied so I went to Legal Aid, and they wouldn't help me. But, they did refer [me to] a private lawyer. So I went and talked to her and here she was really nice. She went in front of the judge and everything, and she got my benefits for me, back-pay for, I think it was, two years. But, she took one-third of it after, you know, I got it.*

Similarly, a second consumer reported that she was receiving help through a "student lawyer" from the University of Colorado, Boulder:

> *I had a good one there and he's still working with me. . . . Students are still coming over here at a certain time to help with Social Security, child support, whatever.*

Additional Questions Specific to Service Providers

At the recommendation of PAC members, service providers were asked if their agencies had **any discretionary monies** that could be used to hire a task force coordinator. The purpose of the task force (in which several members of the PAC had agreed to participate) would be to act on issues related to meeting the identified needs of American Indians with disabilities. One service provider reported to have some discretionary funds, but was not willing to say how much was available until the task force determined what the financial needs would be. It was suggested that the task force contact this individual once the financial needs were determined.

It was also suggested that there were three university programs in Colorado with federal grant monies from which resources might be drawn: "There may be a way to pool resources." The agency representative from Denver Options suggested that the task force submit a proposal to that agency. Similarly, it was indicated that the Developmental Disabilities Planning Council might have resources available.

As a follow-up to this question, service providers were asked if they had an Indian staff person who could be assigned, as part of her/his responsibilities, to assist with the coordination of the task force; PAC members were also concerned that such an assignment be accompanied with release time from other duties as necessary so that a situation of overburdening the Indian staff person would not occur. One participant commented, "I think that would be a possibility."

In response to the consumer focus group participants' expressed **needs to meet with service agency representatives**, it was recommended by service providers that a clearinghouse be developed to collect and distribute information about the services available in Denver. Service providers also agreed that there should be a task force--"a group of people that continually look at the issues." Additionally, one service provider reported that a job fair for persons with disabilities was going to be sponsored by the agency she represented, with information and support available to consumers, as well as quarterly "town hall" meetings.

Given the lack of action taken after the 1990 needs assessment, service providers were asked to give their recommendations as to **who should receive copies of the 1993 follow-up report?** Participants suggested sending copies of the report to all of the service providers in the city and county of Denver. Other suggestions included *not* mailing the report to people, but hand-carrying it to relevant persons as a means of advertising the need for services for American Indians with disabilities, as well as establishing relationships in the community. Additionally, participants commented:

> *. . . seems like we're talking a lot about advocacy and legal issues and one player that hasn't been involved is the Legal Center for the Handicapped who work with disabilities. I think they have targeted Native Americans as an under-served population and what role can they play in some of the future activities.*
>
> *I would encourage you to send it to legislators also. They do pay attention to this. And state legislators in particular.*

The service provider focus group ended by addressing the **issue of transportation**. The comment was made that transportation had been an ongoing problem for persons with disabilities, and was particularly difficult to resolve in terms of focusing on American Indians in Denver as "a group." Indian people in Denver do not live primarily concentrated in one neighborhood, but dispersed throughout the metropolitan area. Service providers concluded that the problem of

accessible transportation would be an important topic for discussion and solution by the task force.

DISCUSSION

During three, three-hour focus group interviews, participants were asked to comment on the extent to which they had witnessed, since the 1990 AIRRTC needs assessment, the development of programs designed to meet the identified needs of American Indians with disabilities--programs such as in-home outreach, case-management, specialized vocational rehabilitation services, and programs with emphasis on the "health and wellness" aspects of disability. The participants were also asked to comment on the extent to which they had witnessed increased employment opportunities for Indian people with disabilities; efforts to train, hire, and retain American Indian personnel; and self-advocacy among Indian people with disabilities. They were asked to comment on the assistance with "community building efforts" which they, or their agencies, had provided; the significance of focusing on the needs of American Indians *with disabilities* as an issue; the role of the university-based research team in responding to the identified needs; the role of the American Indian community; and strategies for developing linkages among service providers. Finally, participants were asked to give their opinions regarding responsibility for action, that is, who is responsible for ensuring that action takes place to effect change based on identified needs--an Indian leader operating from a service agency base? Consumers who have organized a grassroots movement? The university-based research team?

A few PAC members and service providers indicated that change had occurred in Denver, indeed was continuing to occur, in services provided to American Indians with disabilities as a result of the 1990 needs assessment. Colorado Rehabilitation Services, for example, sent counselors to the Denver Indian Center and to the Denver Indian Health and Family Services to meet with prospective clients [This effort was not considered by agency representatives to have been particularly successful; in home outreach was not attempted by the agency]. The Social Security Administration increased its information sharing and outreach efforts.

However, in the focus group interview of consumers, participants reported *no difference* in their perception of service delivery. These participants were not

aware, for example, of outreach services, case-management, or any specialized vocational rehabilitation service provided for older Indians with multiple disabilities. Consumers did note that the program, Seniors Incorporated, had helped an elderly consumer find a job. Consumers identified at least three areas of service which remained, for them, significantly inadequate--transportation, information about services, and dental services.

Some service agencies reported activities which would benefit Indian people with disabilities, but which had no relationship to the 1990 needs assessment. For example, Eagle Lodge, a substance abuse treatment program, reported writing a grant proposal to provide case-management services to Indian people with disabilities.

In terms of effecting change, consumers felt that a grassroots movement for self-advocacy was needed, as well as a local leader to organize the movement. Consumers expressed the belief that the university-based research team should continue its involvement in a community beyond submitting a written report of research results. The PAC participants, as well as other service providers, also expressed the opinion that the university research team should be available, following a research project, to provide technical assistance and/or support to the community as necessary.

Progress Toward Change

In response to the focus group questions, PAC members and service providers, more often than not, identified: (a) service delivery roadblocks; (b) attempts which had been made to initiate change, but had failed; (c) and current levels of service delivery. For example, regarding the hiring, training, and retaining Indian personnel, PAC members and service providers cited a lack of response to their recruitment efforts. Specific comments included:

> *I think a year or so ago, we did try to encourage the Denver Indian Center to apply for an establishment grant which targeted serving underserved people and we felt that the grant that was [drafted] really did fit the model of trying to develop some outreach. Unfortunately, the Center didn't apply.*
>
> *We also had that same problem during this period of time. Social Security had a grant that different organizations could have applied for and one packet was sent to the Denver Indian Center, . . . and no action was taken. . . .*
>
> *I noticed that one of our staff had been involved in the survey. Our organization went through significant change. I'm not sure that this survey was communicated to anybody. And speaking with our executive director, he*

was not particularly familiar with the survey. And he's been with the organization about a year and a half now. So, I'm not sure how this was disbursed--if it got to everybody that it needed to within our organization.

Responsibility for Action

Participants were asked if anyone even cared about the issue--Indian people with disabilities, or if there were other issues that need to be addressed before this particular focus could be taken. For example, one of the co-moderators commented:

The bigger issue is, we have few in Indian leadership, and those individuals in leadership wear so many different hats that the demands are just far greater than, you know, the supply. . . . That's the big issue. We want very much to make sure we don't force our leaders out because of stress and because of burnout--because of frustration levels. That's the bigger issue.

PAC participants expressed a strong positive response regarding the need to continue focusing on meeting the needs of American Indians with disabilities. Consumers discussed the need for self-advocacy and support groups, with service providers suggesting that, indeed, the community must identify its own needs and solutions to problems. For example, PAC members identified specific steps necessary to maximize linkages and the flow of information: (a) establish a network of relevant service providers and (b) work to increase federal funds for urban Indian programs. Participants commented:

My sense is that most of the service agencies have a mandate, a school they're going to serve, and they pretty much focus on that particular group right there. Once in a while they'll look over to sister agencies, but I don't think there's too much of that.

. . . I read this study very closely and what we need in this community is a tremendous coordination of services here. And I think it's incumbent upon the Indian community to establish the responsibility and carry out that coordination of services. . . . I think the most positive product will be that we will start expending some positive energies and correcting the situation. It's been too long ignored, overlooked.

You have a lot of well-intentioned people who really don't understand how business is done, or have picked up bad habits and don't know how to change. What worked in 1970 is not applicable today. And providers themselves are really stressing under how to change that--moving from centralized management systems to decentralized, in-home, where the people are, rather than bringing the people here.

. . . I think some kind of local networking group needs to be established so we don't have to depend on Flagstaff coming in here and telling us or helping us to resolve issues, you know. I mean, I think that we have to establish a local base–a network. . . . I guess my frustration is in trying to establish a network and not having people get killed in trying to carry out the charge because of the responsibility. . . . It's a 24-hour a day job; people have 24-hour a day needs and one person can't do that.

Specifically, regarding the role of the university-based research team in effecting change, PAC members suggested that the researchers needed to return to the community upon completion of the research in order to facilitate any action which must be taken to ensure that recommendations are carried out. Emphasis was placed on the need for the research team to first consult with the community, rather than return as a paternalistic community organizer. For example, it was noted that the university-based research team could assist local communities in understanding federal legislation which affects them.

Consumer responses echoed those of the PAC members, indicating a need for the university-based research team to not only identify the problems, but to assist in solving them. Service providers likewise expressed a need for the university-based research team to bring the results back to the community and assist community members in understanding what was found in the research; a need for training following the research was also stressed. One service provider commented:

And truthfully, I have been in this field in Denver for 25 years and it [the needs of Indian people with disabilities] hasn't been a hot topic at most of the organizations or meetings I've been to. We're missing the Native American population. Really hasn't been to the forefront of awareness. I've not heard it in state level meetings; I've not heard it in city meetings. I don't think people are aware. I think we have a tremendous amount of education to do . . . .

CONCLUSIONS AND RECOMMENDATIONS

The findings of this study indicated that minimal changes in service delivery designed to benefit American Indians with disabilities had occurred since the completion of the 1990 needs assessment. PAC members and service providers pointed to a few specific actions they had taken with regard to improving services for American Indians with disabilities; however, the vast majority of dialogue during the focus group interviews focused on what could not be done, what had not

happened, and examples of the current level of service delivery (which typically did not target Indian people with disabilities).

An information gap existed between service providers and consumers. In addition, a coordinated effort among service providers to pool their resources and to find ways of improving their services to American Indians with disabilities, appeared to be lacking. In part, this lack of coordination may have been due to changes in leadership at both of the Indian centers involved in the 1990 needs assessment--changes which occurred soon after the completion of the study. One Indian service provider commented:

> *The fact that DIHFS [Denver Indian Health and Family Services] is going through a transition is something that all three of the primary [Indian] agencies are continually going through--some type of transition. And it is extremely difficult to maintain any type of continuity with services or even directions or goals. The management is always changing. I think that's something that needs to be addressed because we have to establish a process, we have to establish a program, and we have to establish continuity. I'm encouraged by the fact we have many people here who are willing to help our community. First of all, most importantly, it's incumbent upon us to set the goals, to take this information . . . and to do something with it. . . . Hopefully, I think that the three [Indian] agencies can get together and put together a universal case-management system. . . . What is needed is the tremendous coordination of efforts. That's what we need first. We need to establish a case-management system. What's happening, I think, is that the Indian community has got to move . . . . I think there is tremendous effort by individual people, you know, individual people within the community, but, we all have to hook up together and work together.*

The focus group proceedings revealed a community willing and interested *to discuss* issues relevant to American Indians with disabilities. The discussions of PAC members, consumers, and service providers reflected a recognition of the problems faced by American Indians with disabilities, a desire to work toward problem resolution, and an interest in how to make changes. However, as one of the co-moderators commented:

> *And that's kind of been real encouraging that there is in fact interest. Once the word came out that we were having this service provider [focus] group, suddenly, people came out of the woodwork and said, "Yes," we want to be part of it--linking with the American Indians here. And how much of that is at face value, kind of a superficial interest? That way they can go back to the*

communities and say, "Yes, we're involved in the Native American community," but never follow up on that. . . . I'm wondering whether or not these agencies have pockets of money that can actually be tailored to serve, specifically, Indian people.

A service provider commented, "We got to put our money where our mouth is."

During the focus group meetings, PAC members, consumers, and service providers volunteered to join a task force and to provide monies for its administration in order to work together for improved service delivery. There appeared to be a consensus that, even with such a task face, a "leader" was needed. Participants commented:

I think you've got plenty of people you can pull together. What you don't have is someone that can do the follow-up, the staffing. The calling up, putting together the meeting, the minutes, whatever it takes to follow-up. It's really a quarterback. Resources to get that person.

My point is, we don't have extra money--that doesn't mean we are excused. I think in our office we have a Native American initiative. . . . You can have staff direct a portion of their energy toward meeting some of the goals. So I think whether or not they have a special pool of money, you can still do something to cause some of these things to happen.

Consumers stated the need to come together and effect change through a grassroots movement. Of coming together to share their concerns at the focus group meeting, consumers commented:

To me, it makes me feel good to share problems or medications or whatever's wrong. . . . And I am really happy I could share mine, and they listen to me, and they can share theirs and talk about it, and see what can be done. . . . It's very open and [possible] for them to say what they want to say among each other because we're all elderlies or Indian people--different nationalities. I think it is really good. I sit and listen and they listen to my complaints.

Me, myself, I feel good about this. Now I don't have to carry the whole load myself. I open up and I think my son will get some help, hopefully. That's the way I feel. I think this is a good way to do it.

Just sharing helps.

Finally, participants agreed that the university-based research team should not only report its findings, but should assist the community in implementing

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recommended changes. [It should be noted that the community has found ways to utilize the 1990 needs assessment unanticipated by the research team. For example, Mr. Phil Sidoff, Case-management Coordinator/Special Projects, Eagle Lodge, has reported that instrumentation developed by AIRRTC researchers for the 1990 needs assessment is currently being used at Eagle Lodge as part of case-management assessment activities (personal communication, September 1, 1994).]

Recommendations

PAC members, consumers, and service providers were asked to offer their recommendations regarding the issues discussed. The following recommendations, directed to those agencies and consumers who participated in the 1990 needs assessment, as well as the 1993 follow-up study, include both suggestions from the focus group participants, as well as from members of the research team:

1. Form a self-help/support group among American Indian persons with disabilities.

2. Form a task force to continually look at the issues facing American Indians with disabilities; for example, on an on-going basis, work with a consumer group to establish a "town hall" forum at which Indian people with disabilities can communicate with service providers.

3. Develop a central clearinghouse in the Indian community for services that are available to people with disabilities.

4. Aggressively support interested service providers and consumers in developing funds that would target meeting the identified needs of American Indians with disabilities. As one consumer said, "We would definitely have to have some funding because it takes money to get around, you know."

5. Become educated regarding issues of concern to persons with disabilities such as the Americans with Disabilities Act (ADA); in particular, the types of accessible transportation consumers should expect under ADA should be of interest to the Denver community.

6. Request technical assistance from the American Indian Rehabilitation Research and Training Center to organize a leadership workshop in Denver. Participants at this workshop could, for example, focus on developing skills in leadership, grant writing, networking, advocacy, or needs identified by the community.

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Appendix A

Letter of Invitation to Consumer and Service Provider Interviewees

and

Profile of Focus Group Participants

NORTHERN ARIZONA UNIVERSITY

INSTITUTE FOR HUMAN DEVELOPMENT
ARIZONA UNIVERSITY AFFILIATED PROGRAM

November 20, 1992

Dear :

You may remember that the American Indian Rehabilitation Research and Training Center conducted a research study to find out the services needed for American Indians with disabilities in the Denver metropolitan area in 1990. We appreciate your contribution to the successful completion of that study.

Presently, Dr. Catherine Marshall and I are planning to conduct a follow-up study to determine if there were changes in the services provided to American Indians with disabilities as result of our earlier research. The follow-up study will take place during the week of April 5-9, 1993. We hope to talk with individuals with disabilities, and service providers in group interviews. American Indians with disabilities will receive $25.00 for taking part in the group interview. A project advisory committee will help us to plan and organize our research.

If you are willing to participate in the group interview, or with the project advisory committee, please fill out the enclosed form and return it by December 15, 1992. A self-addressed and stamped envelop is enclosed for your convenience.

If you know someone who did not participate in our earlier study, but would like to serve on our project advisory committee or in the focus group interview, please include that person's name and address on the form.

Sincerely,

R. C. Saravanabhavan, Ed.D.
Instructional Specialist Sr./ Adjunct Professor

pc: Catherine A. Marshall, Ph.D.

AMERICAN INDIAN REHABILITATION RESEARCH AND TRAINING CENTER
PO Box 5630 Flagstaff, AZ 86011-5630 USA (602) 523-4791 FAX 523-9127 TDD 523-1695

American Indian Rehabilitation Research and Training Center
Northern Arizona University
P O Box 5630
Flagstaff AZ 86011

DENVER FOLLOW-UP STUDY

I am willing to participate in the follow-up study which you are going to conduct in Denver. (Please mark the appropriate box with a ✓ sign.)

❒ Please include my name on the *group interviewee list.*

Disability: _____

Tribal Affiliation: _____

Name: _____
First name Last name

Street: _____
Apartment/Door # and name of street

City: _____ State _____ Zip: _____

Telephone: (____)_____

❒ I am interested in serving as a member of the *project advisory committee.*

Disability: _____

Tribal Affiliation: _____

Name: _____
First name Last name

Street: _____
Apartment/Door # and name of street

City: _____ State _____ Zip: _____

Telephone: (____)_____

❒ Please contact the person whose name and address I have given below. *She/He may be interested in participating in the group interview or on the project advisory committee.*

Name: _____
First name Last name

Street: _____
Apartment/Door # and name of street

City: _____ State: CO Zip: _____

Telephone: (____)_____

Profile of Focus Group Participants
Denver Follow-up, 1993

Name of Participant:_____

Address:_____

Telephone:_____

1. Tribal Affiliation_____
2. Disability_____
3. Age _____
4. Were you interviewed in 1990 (Phase 1)? ❒ Yes ❒ No
5. What schedule is most convenient for you on April 7, 1993? (Please check box)

A. ❒. Focus group meeting, including lunch

11:00	-	12:00	Focus group meeting for consumers
12:00	-	1:00	Lunch
1:00	-	3:00	Focus group continues

B. ❒. Focus group meeting, including supper

5:00	-	6:00	Focus group meeting for consumers
6:00	-	7:00	Supper
7:00	-	9:00	Focus group continues

C. ❒. Either the lunch schedule or the supper schedule is OK.

6. Would you prefer to use your native language or a sign language during the meeting?
❒ Yes ❒ No

If Yes, an interpreter will be provided.

a. Preferred Native Language_____

b. Preferred Sign language_____

7. We are sincerely interested in gathering your comments. Therefore, we need to tape record the meeting. However, your comments will not be associated with your name in any reports that may come from the meetings. Do you have any concerns about having the meeting tape-recorded? ❒ Yes ❒ No

If Yes, please tell us your concerns:

_____

_____

If you have any questions, please call:

Catherine Marshall or R. C. Saravanabhavan at 1-800-553-0714
Vera Mitchell at (303) 733-6674
Michael Aragon at (303) 393-0233

Appendix B

Focus Group Questions

Focus Group Questions Posed to All Groups

1. To what extent do service agencies in Denver currently conduct in-home outreach efforts to American Indians with disabilities? What efforts, if any, were made to establish such programs after the study was conducted? To what extent were these efforts successful? What problems were encountered, if any? Should any efforts be taken now to establish such a program, and by whom?

2. To what extent do service agencies in Denver currently offer case-management services to American Indians with disabilities? What efforts, if any, were made to establish such programs after the study was conducted? To what extent were these efforts successful? What problems were encountered, if any? Should any efforts be taken now to establish such a program, and by whom?

3. Are vocational rehabilitation services which focus on the special needs of an aging work-force with multiple disabilities currently available within the American Indian community? What efforts, if any, were made to establish such programs after the study was conducted? To what extent were these efforts successful? What problems were encountered, if any? Should any efforts be taken now to establish such a program, and by whom?

4. What efforts, if any, were made to increase employment opportunities for American Indians with disabilities after the study was conducted? To what extent were these efforts successful? What problems were encountered, if any? Should any efforts be taken now to establish such a program, and by whom?

5. What efforts, if any, were made by American Indians with disabilities to unite themselves as a "community" and engage in self-advocacy after the study was conducted? To what extent were these efforts successful? What problems were encountered, if any? Should any efforts be taken now to establish such a program, and by whom?

6. To what extent did community service agencies assist consumers with their "community-building efforts?" Have any education and information programs been offered within the Indian community, for example, in the area of legal rights, the Americans with Disabilities Act? What problems were encountered, if any? Should any efforts be taken now to establish such a program, and by whom?

7. To what extent do Indian health agencies in Denver currently offer programs which stress the "health and wellness" aspects of disability? What efforts, if any, were made to establish such programs after the study was conducted? To what extent were these efforts successful? What problems were encountered, if any? Should any efforts be taken now to establish such a program, and by whom?

8. What efforts have been taken by service agencies in Denver to train, hire, and retain American Indian personnel to serve American Indians with disabilities?

9. Does anyone even care about the above issues, including Indian people with disabilities in Denver? In other words, should we actually be asking different questions about different issues? Where does the Indian community want to put its energy? What indeed are the most immediate concerns of the Indian community in Denver?

10. What should the role of the university-based research team be as regards ensuring that action takes place after data are gathered, summarized, and returned to the community? Should we be concerned with whether or not action takes place, or is this concern solely that of the community?

11. To what extent should any action taken be the result of the efforts of an Indian leader versus the results of the efforts of a grassroots movement?

12. We have spoken of the Indian community. To what extent does a unified Indian community in Denver exist? To what extent is it willing to advocate for Indian people with disabilities. What specific steps need to be taken, and by whom, to ensure that this advocacy takes place?

13. What specific steps need to take place to maximize linkages and the flow of information among services in Denver which do exist to serve Indian people, both in terms of available services as well as available moneys or opportunities for funding?

14. To what extent does the Indian community utilize non-Indian service systems and funding sources?

15. What specific recommendations would you like to see in the report of the follow-up study? Would you be willing to participate in a task force to ensure that these specific recommendations are carried out?

Additional Questions Specific to Consumers

Following their response to the above 15 questions, PAC members were asked to identify additional questions which should be asked of the consumer and the service provider focus groups; consumers were asked to identify additional questions which should be asked of the service provider focus group. Subsequently, the consumer focus group members were asked to respond to the following questions:

1. What kind of problems, if any, have you encountered when applying for services during the past three years?

2. What services, if any, did you need in the past three years that you did not get?

3. Would you like to be a member of a support group with other American Indians with disabilities?

4. Have you ever needed a service but did not ask for it? If yes, why didn't you ask for the service?

5. Do you seek and/or obtain services from a non-Indian agency?

6. Please describe your disability. How does it keep you from doing anything you need or want to do?

Additional Questions Specific to Service Providers

1. Do you have discretionary moneys in your budgets that you could contribute to hiring a person to coordinate the efforts of the task force?

2. Do you have an Indian staff person who could be assigned part of the responsibilities to help coordinate the task force and/or to participate in some other way with release time from other duties as necessary?

3. What do you think should be done with these data; who do you think should receive copies of the final report?

Appendix C

Agenda of Focus Groups

The Assessment of a Model for Determining Community-Based Needs of American Indians with Disabilities: Follow-up in Denver, Colorado

Focus Group Interviews

April 6, 7, & 8, 1993

AGENDA

11:00 - 11:05	**Gathering of Participants** Distribution of Materials (Denver Final Report, Executive Summary, Journal of Rehabilitation Article, AIRRTC brochure)
11:05 - 11:30	**Introductions** a) Name b) Role of the individual c) Interest in the process; why was she/he motivated to participate d) Represent a particular agency? Private citizen?
11:30 - 11:45	**Overview of Agenda and "Ground Rules"** *Mike Aragon*
11:45 - 12:00	**Signing Informed Consent Forms and Interviewee Billing Statements**
12:00 - 12:45	**Lunch** Summary of Research: *Catherine Marshall, Ph.D.* Presentation: *Geno Pichette* Reminder of "Ground Rules" *Mike Aragon*
12:45 - 1:00	**Break**
1:00 - 3:00	**Focus Group Interview** Questions as follows asked by Mike Aragon (and Vera Mitchell for the consumer group interview) with follow-up as needed by Catherine Marshall

Appendix D

Informed Consent Form

and

Interviewee Billing Statement for Consumer Interviewees

INSTITUTE FOR HUMAN DEVELOPMENT
ARIZONA UNIVERSITY AFFILIATED PROGRAM

American Indians with Disabilities
Community Needs Assessment
Follow-up
Denver, Colorado

Informed Consent Form
for use of the Focus Group Interview Information
for Research Purposes

I hereby authorize representatives of the American Indian Rehabilitation Research and Training Center (AIRRTC) to use the information obtained from me during the focus group interview on _____ (date) for research purposes.

I understand that information from the focus group interview will never be reported in such a way that I can be identified.

I understand that the transcripts and audio-tapes of the focus group interview will be filed by the AIRRTC in an area with restricted access. Only authorized representatives of the AIRRTC will have access to the transcripts and audio-tapes.

I understand that I can receive answers to my questions regarding this project at any time by contacting the AIRRTC (at 1-800-553-0714) or the on-site research consultants in Denver (Vera Mitchell, at 733-6674; and Michael Aragon, at 393--0233).

I understand that I am free to withdraw from participating in the project at any time without incurring ill will.

I understand that I will receive $25 in compensation for my time (approximately 4 hours) spent during the focus group interview.

_____ _____
Interviewee's Signature Date

_____ _____
Parent/Legal Guardian Signature Date

_____ _____
Focus Group Moderator's Signature Date

AMERICAN INDIAN REHABILITATION RESEARCH AND TRAINING CENTER
PO Box 5630 Flagstaff, AZ 86011-5630 USA (602) 523-4791 FAX 523-9127 TDD 523-1695

INSTITUTE FOR HUMAN DEVELOPMENT
ARIZONA UNIVERSITY AFFILIATED PROGRAM

American Indians with Disabilities
Community Needs Assessment
Follow-up
Denver, Colorado

Informed Consent Form
for use of the Focus Group Interview Information
for Research Purposes

I hereby authorize representatives of the American Indian Rehabilitation Research and Training Center (AIRRTC) to use the information obtained from me during the focus group interview on _____ (date) for research purposes.

I understand that information from the focus group interview will never be reported in such a way that I can be identified.

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I understand that I can receive answers to my questions regarding this project at any time by contacting the AIRRTC (at 1-800-553-0714) or the on-site research consultants in Denver (Vera Mitchell, at 733-6674; and Michael Aragon, at 393--0233).

I understand that I am free to withdraw from participating in the project at any time without incurring ill will.

_____ _____
Interviewee's Signature Date

_____ _____
Focus Group Moderator's Signature Date

AMERICAN INDIAN REHABILITATION RESEARCH AND TRAINING CENTER
PO Box 5630 Flagstaff, AZ 86011-5630 USA (602) 523-4791 FAX 523-9127 TDD 523-1695

R - 29
Denver Follow-up, 1993
Interviewee Billing Statement

Name _____

Address _____

City _____ State _____ Zip _____

Phone # _____

Social Security # _____

I understand I will receive $25.00 in approximately four to six weeks for participation in the focus group interview. I understand that this sum is given to assist me with transportation to the interview site, and to make any other personal arrangements necessary to take part in the focus group interview.

_____ _____

Signature of Interviewee Date